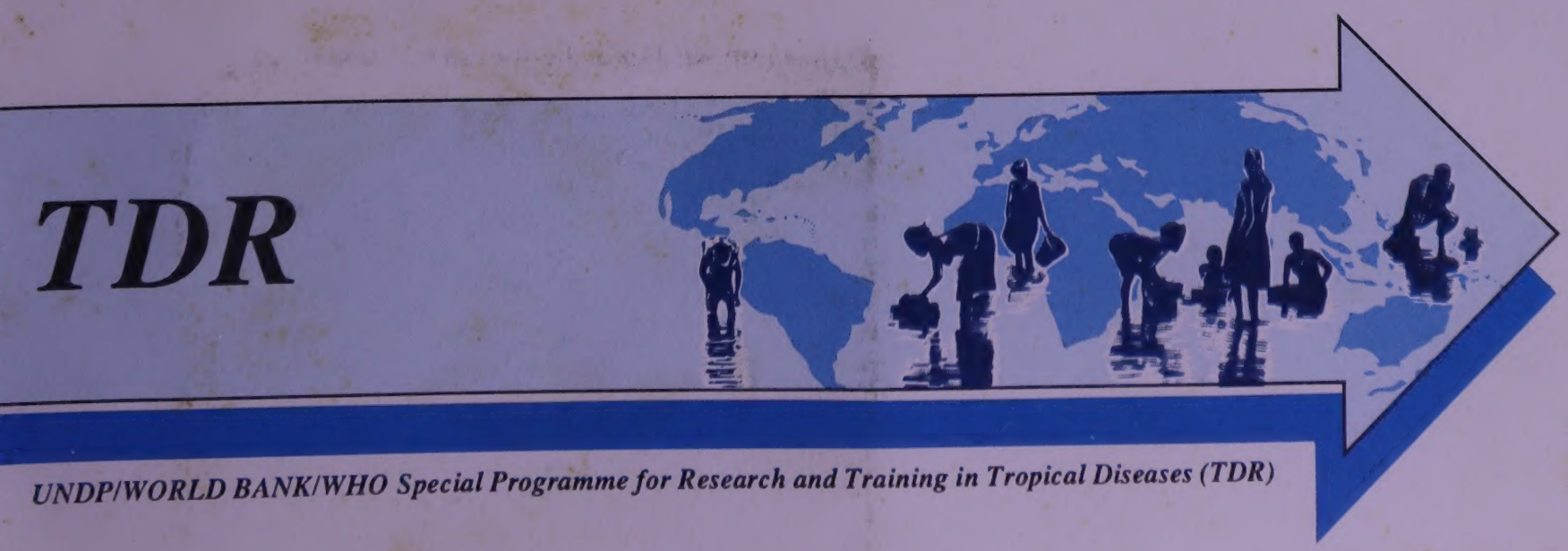
Social and Economic Research Project Reports *No. 16*

Khi thut, "The Disease of Social Loathing": An Anthropological Study of the Stigma of Leprosy in Rural North-East Thailand

Pimpawun Boonmongkon

**Faculty of Social Science and Humanities,
Mahidol University, Salaya, Nakornpathom,
73170, Thailand.**

**Final report of a project supported by
the TDR Social and Economic Research component**



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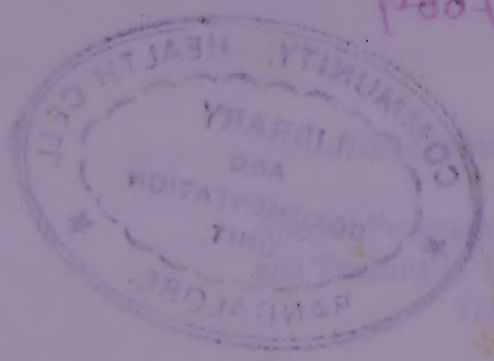

(November 1994)

UNDP/WORLD BANK/WHO Special Programme for Research and Training in Tropical Diseases (TDR)

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Foreword

The UNDP/WORLD BANK/WHO Special Programme for Research and Training in Tropical Diseases (TDR) is a globally coordinated effort to bring the resources of modern science to bear on the control of major tropical diseases: malaria, schistosomiasis, filariasis (including onchocerciasis), the trypanosomiases (both African sleeping sickness and the American form, Chagas' disease), the leishmaniases and leprosy. The Programme has two interdependent objectives:

- To develop new methods of preventing, diagnosing and treating selected tropical diseases, methods that would be applicable, acceptable and affordable by developing countries, require minimal skills or supervision and be readily integrated into the health services of these countries;

- To strengthen -- through training in biomedical and social sciences and through support to institutions -- the capability of developing countries to undertake the research required to develop these new disease control technologies.

The *Social and Economic Research Project Reports* series represents a communication venture undertaken by TDR's Social and Economic Research (SER) component. This series was launched in 1987 to facilitate and increase communication among social scientists and researchers in related disciplines carrying out research on social and economic aspects of tropical diseases and to disseminate social and economic research results to disease control personnel and government officials concerned with improving the effectiveness of tropical disease control.

Research reports published in this series are final reports of projects funded by TDR and usually include more material than ordinarily published in peer review journal articles. TDR considers this material to be valuable both for investigators involved in the study of social and economic aspects of tropical diseases and for professionals involved in training programmes in the social sciences, economics and public health. The series should acquaint those working on similar problems with approaches undertaken by others, in order to test new approaches in different settings, and should provide useful information to personnel in disease control programmes and related agencies.

Although SER, as of 1 January 1994, was integrated into an Applied Field Research (AFR) component of the TDR Programme, the AFR Steering Committee considers that the series deserves to be continued so that results of the social and economic research in TDR will continue to be disseminated.

Tore Godal, Director

Special Programme for Research
and Training in Tropical Diseases
TDR

Glossary

baap	sin or demerit
baht	twenty-five bahts equal approximately one dollar
boon	merit
din	earth
fai	fire
Isaan	North-East Thailand
khi	faeces, used as a prefix
khihung	jealous
khihuu	earwax
khikhait	lazy
khikrai	skin scurf
khimuuk	mucus
khireaw	ugly
khi thut	North-East Thai term for leprosy
khon	a person
khon Isaan	a north-easterner
Khonkean	a province of North-East Thailand
khon khi thut	a leper
khut thung	lack or shortening of fingers and toes
kreng chai	part of the code of appropriate behaviour among the Thai, the desire to be self-effacing, respectful, and considerate
lom	wind
mae	a North-East Thai term for a germ
mao moan	a magician who treats patients by using sacred water and magic spells
mettasongsarn	Buddhist ideology of compassion and mercy
Nakhon Ratchasima	a province of North-East Thailand
narm	water
phi nawng	siblings
phum thaan thaan thum	low immunity
rai	one rai is equal to .4 acres
rok	disease
rok nuew nun	"that kind of disease"
rok nun	"that disease"
rok ruan	white patches, leprosy
rok sungkhom rungkhiat	the disease of social loathing
rok yai	the Central Thai term for leprosy, which literally means "a great disease"
ruet lom mai dee	imbalance of blood and wind elements
sai lud douw khan	a person sharing the same blood group
thut	a North-Eastern Thai term for leprosy

Terms listed above are from both the Thai and North-Eastern Thai languages. Words that are not described as North-East Thai terms are used by both Thai and North-East Thai speakers. All Thai terms used in this report have been transcribed according to the transliteration system of the Royal Thai Government (see Royal Institute, *Romanization Guide for Thai script,* Bangkok, Royal Institute, 1968).

Preface

The goal of the social and economic research supported by TDR has been to provide results that will help to reduce the burden associated with the targeted tropical diseases. In the last 5–10 years, it has been TDR's philosophy that social and economic research is required at a number of levels, from the development and use of "rapid assessment" methodologies to more in-depth studies, requiring longer periods of time in the field, designed to understand the nature and rationale for various types of human behaviour. This Research Project Report falls into the latter category, being a detailed ethnographic study of the stigma associated with leprosy in a part of Northern Thailand, undertaken by a skilled medical anthropologist.

In common with most other studies of the same topic, stigma is shown to be strongly associated with leprosy. However, in this study there was some variability in the stigmatization process. Dr Pimpawun shows that this is partly a result of conflicting factors that coexist in Thai society, some of which work toward stigmatization (e.g. the Buddhist notion of leprosy as an incurable disease related to sinful acts committed by the patient), and others that work to mitigate the stigmatization (e.g. the Buddhist ideology of compassion and mercy to those who are less fortunate). Of particular interest are the policy implications, which do not simply recommend trying to change the behaviour of villagers. There are implications for the development of appropriate health education materials and for the behaviour of health workers. For example, some of the health education materials used at the time of the study, showing the more disfiguring sequelae of the disease, reinforced community fears and made healthy people want to keep patients at a distance. Even the name health workers commonly used to label the disease—the "disease of social loathing"—had a similar effect. The researcher makes a number of valuable suggestions about how these problems can be overcome.

David B. Evans & Carol Vlassoff
Applied Field Research Group, TDR

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Pimpawun Boonmongkon
November 1994

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CHAPTER 1

THE PROBLEM OF THE STIGMA OF LEPROSY

Introduction

The number of cases of leprosy worldwide has fallen dramatically in recent years, and in 1991 the World Health Organization (WHO) declared its aim to eliminate leprosy as a public health problem by the year 2000. While there is great hope for the success of this effort, critical questions remain unanswered. Social, economic, and political conditions in endemic countries may complicate efforts to eliminate leprosy. It is also unclear whether the stigma associated with leprosy, a significant factor in discouraging infected people from seeking early and regular treatment, is actually decreasing. Finally, we lack a full understanding of the quality of life of leprosy sufferers in their own communities, in terms of their physical, emotional, and social functioning.

Leprosy continues to be a serious public health problem in the developing countries. The population at risk of contracting the disease is large, and more than one-third of all people with leprosy face the threat of progressive and sometimes permanent physical and social disabilities (WHO, 1989). Besides causing anaesthesia of the skin and deformities of the hands and feet, leprosy (along with trachoma) is considered to be the major cause of blindness in the South-East Asia Region (Lechat, 1983).

Only a few of these countries have developed satisfactory health education and rehabilitation programmes designed to combat the stigma of leprosy and to rehabilitate patients. Despite the scientific information and successful treatment now available for leprosy, fear and prejudice associated with the condition remain strong in many countries. In most societies, leprosy is still viewed as a debilitating, incurable, and socially ostracized disease. For this reason, we need continuing intracultural and cross-cultural studies concerning the stigma of leprosy.

The objectives of this study were:

- to assess the extent and forms of the stigma of leprosy that exist in rural Thai society;
- to explore reasons why the stigma of leprosy exists; and
- to understand the medical and psychosocial problems encountered by people with leprosy and their families, and how they cope with these problems.

In Thailand, stigma associated with leprosy varies (Leerapun et al., 1989; Ramasoota, n.d.). The country has faced many changes in terms of social and economic transformation and in advancements in medical technology. This is particularly true in the case of the implementation of multidrug therapy regimens, the so-called rapid and effective treatment for people with leprosy. Owing to these conditions, Thailand is a useful setting for conducting a study on the dynamics of the stigma of leprosy. The research on which this report is based sought to demonstrate the use of anthropology in improving the planning of leprosy control programmes. Hopefully, the knowledge gained from this study will provide information needed to develop effective strategies to combat stigmatization and to promote self-help rehabilitation programmes for prevention of deformities as well as measures to successfully reintegrate people with leprosy into their communities.

Research Methodology

Data collection

This study adopted an ethnographic approach that included a range of methods such as participant observation, oral history, life history, in-depth interviews, analysis of folklore, questionnaire survey, and reviews of Buddhist doctrine, health worker training manuals, and government plans for the leprosy control programme. The diverse data were not collected in isolation, because information collected using one method informs data collection using another (see Table 1).

Ethnography. The ethnographic study was carried out over a nine-month period (from 15 March to 15 December 1991) while I was residing in the village of Noan Pa. During the study, I engaged in participant observation and conducted informal and in-depth interviews with a number of informants, and completed a census of every neighbourhood household. Survey questionnaires were administered to all nonpatient households.

Participant observation. Prominent among my methods of data collection was participant observation. The majority of my time was devoted to observing, and the bulk of my field notes derived from my experience participating in the everyday social lives of nine leprosy patients, ex-patients,[1] and their families, as well as people who interacted with them such as villagers, health workers, and strangers from outside the community. To the extent that I could, I participated actively in the lives of the persons with leprosy and their families in order to understand what it means both to them and to the people around them to have leprosy. My observations focused on daily interactions between patients and nonpatients, their likes and dislikes, fears and ostracism, as well as patients' adaptation to their stigmatized chronic illness. I helped them plough their fields and catch fish in the pond, and participated in patients' social interactions with other villagers. I also accompanied patients to the district hospital, health centre, and leprosy colony, as well as to Bangkok, and went with them to gambling events, cockfights, and grocery shops.

This method allowed me to observe firsthand the experiences of stigmatized people. For example, while participating in one village ritual ceremony, a leprosy patient with body deformities who was walking past a group of drinkers was teased by a man, "Don't let him drink with us; he will spread his disease."

Oral and life histories. Fifteen oral history interviews were conducted with 5 elderly Noan Pa residents. Interviews were tape-recorded, and the tapes were then transcribed. In addition, life-history interviews were completed with 15 patients and former patients and their families in Noan Pa village and 5 of the other 13 villages in the vicinity. These were conducted to assess lifelong medical and social experiences associated with leprosy for infected people and their families.

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[1]In this report, I sometimes refer to my subjects as "patients" and "ex-patients." I am aware that the terms "patients" and "ex-patients" carry certain connotations, in the sense that they imply a medicalization of individuals. However, I do not mean to have the readers draw such inferences. I only use these terms to reflect the fact the subjects were presently or had been under treatment. I also use the terms "people with leprosy," "leprosy sufferers," and "infected people" to refer to both "patients" and "ex-patients" throughout this report.

Table 1: Summary of the subject population

Groups	Noan Pa village	Other 13 villages	Total
Method: Life-history			
Patients			
– male	3	2	5
– female	2	1	3
Ex-patients			
– male	1	2	3
– female	3	1	4
Family members			
– wife	6	2	8
– husband	3	–	3
– daughter	2	–	2
– father/mother	–	2	2
Method: In-depth interview			
Patients			
– male	–	2	2
– female	–	3	3
Ex-patients			
– male	–	23	23
– female	–	17	17
Method: Standardized questionnaire			
Villagers			
– male	37	–	37
– female	31	–	31
Method: In-depth interview			
Village leaders			
– Village headman	1	4	5
– Village health volunteer	4	4	8
– Traditional healer/monk	8	–	8
Health staff*			
– Leprosy worker	–	–	2
– Health centre staff	–	–	5
– District hospital staff	–	–	3

*Numbers for health staff appear only in the "Total" column because while health staff serve the population from Noan Pa and the other 13 villages, they are stationed outside the villages at provincial, district, and subdistrict locations.

In-depth interviews. In-depth interviews with 45 patients and ex-patients and their families from 13 villages in Pu Kum district were performed. The interviews attempted to elicit information about beliefs regarding the cause of disease, health-seeking behaviour related to leprosy, and the social, medical, and emotional ramifications of the disease. Four village leaders and 4 village health volunteers from these same villages were also interviewed to gain information on community attitudes toward leprosy, beliefs about disease causation, and health practices regarding leprosy.

Folklore and document review. This component focused on how folklore and documents (Buddhist doctrine, training manuals, and leprosy control plans) referred to leprosy, and whether they contributed to the producing and/or perpetuating the stigma of leprosy.

Methods of measuring the extent and forms of leprosy stigma

During the second month in the village, my research assistant and I conducted a survey of all households, using structured interviews covering demographic data, family and kinship patterns, economic status, health beliefs and practices, and questions about the intensity and form of the stigma surrounding leprosy that exist in Noan Pa village. Initially, we had a few general and open-ended questions concerning what villagers think about living in the same village with people with leprosy, and interacting with them on a regular basis.

Villagers presented rich information on the fear, repulsion, and ostracism of patients in everyday social interactions. Some villagers, for example, talked about their not wanting to touch rice processed by Jai because he used his claw hands to touch the rice during processing.

After determining some existing patterns of stigmatization of leprosy patients by villagers, I modified my questions. The questions used to elicit the intensity of stigma of leprosy were designed to assess two levels of villagers' views toward leprosy patients. The questions focused (1) on fear of disease contagion, repulsion, and social ostracism, and (2) on behavioural manifestations based on everyday social interactions between patients and communities, specifically, ostracism and seclusion. These questions were formulated from an emic perspective; in other words, they addressed social interactions within the village.

Medical Aspects of Leprosy

Leprosy is a chronic, infectious disease that is caused by the microorganism *Mycobacterium leprae (M. leprae)*. The incubation period is normally about 2–10 years, but periods of up to 27 years have been recorded. The mode of transmission is mainly via nasal droplets from multibacillary patients. *M. Leprae* is regarded as nontoxic, so patients with active leprosy may harbour millions of bacilli yet remain active and apparently healthy. The clinical signs of the disease are largely the result of the host response to the infection. The host–parasite relationship in leprosy is often unstable. Variations in cell-mediated immunity (CMI) and immune complex formation can cause clinical manifestations, called reactions, that are not directly related to bacteriological progress.

Up to 75 per cent of cases may be self-healing leprosy, which results from an effective immune response. If CMI cannot cope with the bacillary invasion, visible clinical disease results. Classification of disease type is generally along a spectrum according to the patient's CMI and is inferred from the numbers of bacilli found in skin and nasal smears. A five-group classification of leprosy is proposed by Ridley & Jopling (1962): Tuberculoid leprosy (TT) is characterized by a more successful CMI response, localized lesions, and very few bacilli, found mainly in the nerves. Lepromatous leprosy (LL), on the other hand, is characterized by diffuse and generalized disease, high bacillary load, and more impaired CMI response. Between these two forms of the disease are the immunologically

unstable borderline forms—borderline tuberculoid (BT), borderline lepromatous (BL), and mid-borderline form (BB), which shows features of both BT and BL (Duncan, 1993:458).

Reactions in leprosy are clinical manifestations caused by alterations in the immune status of the patient. There are two types of reactions: type 1 leprosy (reversal) reaction (RR) and type 2 reaction, or *erythema nodosum leprosum* (ENL). Type 1 leprosy reaction may involve either skin or nerve lesions with resulting neuritus, nerve damage, and permanent deformity. Type 2 reaction is characterized by painful red nodules of the skin that may ulcerate, accompanied by high fever, headache, generalized aches and pains, tender nerves, swollen and tender hands and joints, and so forth (Duncan, 1993:459).

M. leprae affects the nervous system, creates skin damage, and anaesthetizes and paralyzes parts of the body. This can lead to injuries and further infections that may result in deformities if untreated. Leprosy generally begins with the formation of pale or reddish patches on the skin. Patches can also be associated with a local loss of sensation. If untreated, red nodules and thickening of the skin may develop. Due to damage to the peripheral nerves, hands may become claw shaped, feet may become deformed, and paralysis of the eye muscles can prevent the lids from closing. This, in turn, results in the cornea becoming ulcerated. The eyes are easily infected and inflamed, and blindness can follow (Duncan, 1993:458). Accidental injury to insensitive hands and feet during activities of daily living often results in wounds. Painless ulcers can become secondarily infected, and osteomyelitis sets in as infection spreads to involve the small bones of hands and feet. As a result, loss of fingers and toes may occur, and legs and arms may even have to be amputated.

The prospect of a vaccine remains elusive because the bacillus has proven difficult to cultivate in artificial media (Pearson, 1982:229). Leprosy is completely curable and deformities can be totally prevented if early multidrug therapy is taken.

Historical Review of Leprosy Control Programmes in South-East Asian Countries

South-East Asia is considered to be the ancestral home of leprosy, where the disease can be traced back more than 2500 years. It continues to persist in this area at a high endemic level (WHO, 1989). The disease distribution varies within and among countries.

Since at least the 1800s, before a medical treatment for leprosy was found, segregation and isolation of people with leprosy were commonly practised in South-East Asian countries. For example, people with leprosy were taken to small islands by their colonizers in Penang and Singapore. Treatment involving the administration of chaulmoogra oil (expressed from certain trees of the family Flacourtiaceae) was attempted in clinical trials in some countries such as Malaya in the early 1900s, without much success (Rajagopalan, 1983). Missionaries played an active role in providing dapsone (diaphenylsulphone, DDS) treatment in Thailand before the advent of government-sponsored leprosy control programmes. Established in 1940–1950, government control programmes were largely based on early case detection, lifelong dapsone treatment, and case follow-up. Poor case detection and high absenteeism from follow-up treatment were, and continue to be, prominent problems. The causes of these problems are characteristic of the area involved—many are operational, others technical, while some have been attributed to sociocultural and economic factors (Gopalakrishnan, 1986; Rajagopalan & Joo, 1986; Valencia et al., 1984; Valencia, 1986). Following WHO recommendations, monodrug therapy was replaced by a multidrug regimen (MDT) throughout the South-East Asian region. This was due to the emergence of drug resistance, as well as high rates of noncompliance and dropout due to the long duration of follow-up treatment.

Current South-East Asian leprosy control programmes focus on early case detection; household case contact surveillance; treatment of cases with MDT; health education about the cause, types, and forms of leprosy and its treatment; case follow-up after discharge for a number of years; and rehabilitation and deformity prevention. Control programmes now seek to integrate leprosy control with existing medical and health services and primary health care programmes, as well as to provide outpatient care to leprosy patients in order to decrease the prejudice and stigma related to the disease. Problems in leprosy control programmes in most South-East Asian countries include the failure of medical staff (especially from the general health service) to detect the disease at an early stage, the negative attitude and behaviour of the medical staff toward leprosy patients, the lack of community participation in leprosy control programmes, and the lack of successful programmes for social and physical rehabilitation as well as deformity prevention (Rajagopalan, 1983; Rajagopalan & Joo, 1986; Valencia et al., 1984; Valencia, 1986).

Leprosy Control Programmes in Thailand

Throughout Thailand, leprosy prevalence is characterized by marked demographic variation. Leprosy is highly prevalent in the north-east region, the poorest region of the country, while there is a low prevalence rate in the southern, northern, and central parts of the country (3.31, 1.98, 1.76, 1.25 per 10 000 respectively in 1990). The national prevalence rate, estimated to be approximately 5 per 1000 in 1953, was 0.22 per 1000 in 1991. In 1990 approximately 12 068 registered cases were reported nationwide, two-thirds of which were of the multibacillary type (Ministry of Public Health, 1990).

The development of leprosy control in Thailand can be divided chronologically into three phases:

1. Isolation phase (1908–1951). Three leprosaria and 13 leprosy settlements were established during this period. They were operated by missionaries, the Thai government, and nongovernment organizations.

2. Domiciliary treatment with dapsone (1955–1983). A more specialized leprosy control programme was established in 1955, designed to detect existing cases and provide domiciliary treatment with dapsone. After it was proven to lead to successful control, it was partially integrated into general health services in 1971, and fully integrated into the primary health care system in 1976.

3. Domiciliary treatment with MDT (1984–present). In 1982, MDT was initiated in three north-eastern provinces and was gradually implemented throughout the country. The use of MDT has led to a rapid drop in the prevalence rate and numbers of registered cases.

While the leprosy control programme has been successful in medically treating leprosy, only limited attention has been given to the need for physical and social rehabilitation. Health education for destigmatization has not been successful (National Leprosy Expert Committee, 1989; Ramasoota, n.d.). Social ostracism for those suffering from the disease is still institutionalized in terms of legal codes such as marriage law and government hiring procedures. Unfortunately, there is no social movement for addressing these problems.

Because of the existing high rate of deformity, the ongoing and future directions of the leprosy control programme emphasize prevention and rehabilitation of disabilities in patients who have been successfully medically treated so that they can be fully reintegrated into their communities. With this emphasis on community-based rehabilitation, the "self-care in disability prevention" component is the main strategy in present leprosy control. Self-care clinics are set up as health education centres in a health care setting. In these clinics, health care staff demonstrate appropriate self-care practices to people with leprosy and their families in order to prevent or stop the development of deformities. The

community-based rehabilitation programme is also at the early stages of developing an "appropriate model" for community participation in deformity reduction. Self-care clinics have been established in limited locales, such as some Zonal Leprosy Centres, and leprosy colonies.

Definition of Leprosy: Mythology and Metaphor

In many societies leprosy is imbued with a rich and complex mythology that elicits social responses (Gussow, 1964). Berreman (1984) points out that leprosy in India is often called the "illness of untouchability" because it stigmatizes people in a way that renders them essentially "untouchable." Many societies personify leprosy as a manifestation of physical and/or spiritual uncleanliness. Many understand leprosy to be a divine or supernatural punishment for "sinful" or evil deeds (Berreman, 1984; Gerochi, 1986; Gron, 1973; Kumar, 1983; Mutatkar, 1981; Ryrie, 1931; Skinsnes & Elvove, 1970; Valencia et al., 1984). Among the Buddhist Thais, contracting leprosy is the result of having committed sinful acts in past lives (Leerapun et al., 1989; see further details of mythology relating to leprosy among the Buddhist Thai in Chapter 2).

The superstitions and folklore that underlie beliefs of causation and definitions of the disease have ancient roots, notably biblical (Gussow & Tracy, 1968; Kalisch, 1975). In the Old Testament, leprosy is an abomination, a result of ritual uncleanliness. The disease is described under the name of *tsaraath,* derived from *tsara,* which means "cursed by God" (Mangiaterra and Argentina, n.d.). In the New Testament, the stories of Christ miraculously curing the lepers become metaphors for divine salvation (Gussow, 1989). Leprosy has also been described in Chinese (Skinsnes & Elvove, 1970), Indian (Dharmendra, 1967), and Middle Eastern (Gramberg, 1959) historical literature. This literature describes the affliction as a great disease and the result of a punishment for moral evil.

Gussow (1989) states that most major diseases once mythologized in this way have now lost their former emotive power. Only for leprosy do these connotations persist. Waxler (1981) notes that leprosy has been used as a metaphor for "dread," including a mystical component representing social or moral wrongfulness. A negative disease metaphor has been maintained, not only because of "the power of literary imagery" (Gussow, 1989) but also because of social and political factors that will be discussed in the next section.

Stigma of Leprosy as a Social and Cultural Construct

The experiences of various countries reflect how cultural, social, political and historical factors influence the stigma of leprosy in its various forms and their particular social and moral definitions.

The degree to which leprosy is stigmatized varies from one culture to another. In many societies, a person afflicted with leprosy is viewed as a polluted and sinful person (Berreman, 1984; Leerapun et al., 1989; Mutatkar, 1981; Skinsnes & Elvove, 1970; Valencia et al., 1984; Waxler, 1981). There is little or no ostracism in Nigeria and Tanzania (Shiloh 1965). Waxler's cross-cultural analysis of India and Sri Lanka points out that different degrees of stigmatization accompanying leprosy are due to differences in social structure (Waxler, 1981). Leprosy is highly stigmatized in India because of the society's strictly hierarchical caste structure, beliefs, and practices. By contrast, little stigma is attached to leprosy in Sri Lanka, where the caste structure is less hierarchical than that of India; also, Buddhists are more tolerant of differences and show a marked compassion for others.

The articulation of political and economic factors and the appearance of leprosy in Hawaii help to explain the formation of the stigma of leprosy in the United States (Waxler, 1981). In the past, people with leprosy in Hawaii were not stigmatized. During the late nineteenth century, because of fear, racial prejudice, the perceived economic threat from the Chinese labourers in Hawaii, and the death

of Father Damien, who contracted leprosy from his patients, Westerners and native Hawaiians blamed foreign labourers for bringing leprosy. The Chinese were blamed, stigmatized, and excluded. A policy of segregation emerged, and quarantine of the afflicted was strictly enforced, creating further stigmatization.

Studies in the Philippines, Sri Lanka, Nigeria, Tanzania, and Hawaii have all found that the intensification of stigmatization of leprosy is a direct result of Western medicine, mass education programmes, or combined segregation-education programmes for leprosy isolation (Azicate, 1985; Editorial, 1977; Giel & van Luijk, 1970; Gussow & Tracy, 1970; Valencia, 1986; Van Etten & Anten, 1972; Waxler, 1981).

Individual Adaptation to the Stigma of Leprosy

The studies of Bahlinger et al. (1985) and Gussow (1964) show that leprosy patients are obliged simultaneously (1) to cope with psychological and interpersonal challenges, and (2) to adjust to changing medical and social realities. Leprosy patients, like those with other chronic diseases, tend to report more significant life changes than do individuals who have no chronic illness. Studies in Burma, the Philippines, Ethiopia, India, Thailand, Malaysia, and European countries (Berreman, 1984; Duncan, 1993:458; Giel & van Luijk, 1970:196; Gonzales, 1980; Gussow & Tracy, 1968; Leerapun et al., 1989; Rajagopalan & Joo, 1986; Reddy, Satpathy & Krishnan, 1985; Valencia, 1986) point out that leprosy patients attempt to conceal information about the onset of symptoms because of the fear of being sent to an institution or the fear that the treatment will stigmatize them and their families. These studies also reveal that being diagnosed with leprosy brings a person psychological, social, and economic problems, such as self-isolation and withdrawal from normal activities, fatalistic attitudes, apathy, mental illness, loss of family, difficulty in finding a spouse, sexual abstinence, divorce, separation, poverty, job loss, and significantly reduced income.

Health-Seeking Behaviour and Social Experiences of Leprosy Patients in Thailand

Among the northern Thai, Neylan et al. (n.d.) and Leerapun et al. (1989) found that leprosy patients frequently changed practitioners and treatment throughout the course of their illness. Their behaviour was characterized by sequential use of two or three multiple medical resources. Self-medications such as ointments and oral medicines were the most preferred treatment because the symptoms were believed to represent mild skin diseases only. Most patients who chose to go to a leprosy clinic or other government health service during the first stage had relatives who had suffered from leprosy previously. The treatment choice was made by the patient with lay consultants involved in the ongoing process of defining symptoms and perceived severity of illness, and evaluating and monitoring alternative treatment actions. The various therapies were generally evaluated using short-term criteria and often were seen as equal in efficacy. Patients' denial of the disease, because of the stigma attached to it, was also a factor in discontinuing treatment with government health services and/or choosing to initiate self-treatment.

Neylan et al. (n.d.) and others (Brun & Schumacher, 1987) pointed out that for indigenous treatments of leprosy, therapies include sweat baths, oral herbal medicine, cleaning and soaking the skin lesions, and so on. In choosing between indigenous concepts and those of modern medicine, patients believed that herbal treatments are often more accessible and helpful than is modern chemotherapy. They also reported that modern chemotherapeutic treatments such as dapsone are slow to produce results, leading them to prefer alternative therapies.

In one study, Leerapun et al. (1989) concluded that visibility of deformity correlates positively with the level of stigmatization in the community. Some patients perceived rejection by their families and

communities and voluntarily left their homes for treatment at hospitals or colonies. Some patients were treated at home but shunned contact with the community. Spouses and children were more likely to accept and take care of patients, although they too feared contagion. Some couples separated permanently. Community members reacted to leprosy patients with fear and disgust, but their condemnation was not overt.

Leerapun et al. (1989) also mentioned that for most people with leprosy, self-stigmatization precedes negative societal reaction. After the diagnosis, all patients and their families felt anxiety, and patients experienced fear of becoming ostracized and deformed. The level of anxiety differed according to the perceived severity of symptoms, people's familiarity with the disease, and the degree of social support from relatives.

Following treatment and cure, people with visible deformities faced difficulty in adapting. They were ostracized, socially isolated, and became poor and emotionally disturbed. Even those without deformities felt uneasy in their communities and withdrew from some social activities permanently (Leerapun et al., 1989).

The present study is the first to systematically attempt to explain how leprosy stigma arises in Thai society and how it affects the lives of people with the disease. The study also examines the impact of changing biomedical technology in leprosy treatment (i.e. MDT) on the dynamics of stigma and the popular view (or "folk theories") of MDT, that is, how patients, their families, and their communities evaluate the illness when they are told patients have been "cured" with MDT, and further, the effects of these views on the level of stigmatization.

CHAPTER 2

COMMUNITY SETTING

Community Setting

Located in North-East Thailand, the village of Noan Pa,[2] where I resided for nine months during my fieldwork, lies in a semiarid plateau of Nakhon Ratchasima Province. The north-east region of Thailand is known collectively as the Isaan region. The term *Isaan* is used to describe the local people (*khon Isaan*) and their local culture. Isaan culture and language are marked by a mixture of Lao and Khmer cultures (see Figure 1).

The province is 250 kilometres from Bangkok. The village itself lies about 100 kilometres north-east of Nakhon Ratchasima town, the provincial capital, and 16 kilometres from Pu Kum town. The village of Noan Pa is under the jurisdiction of Pu Kum district (see Figure 2). The village was chosen as a study site because it lies in the province and district with one of the highest prevalence rates of leprosy in Thailand (1.1 per 1000 in 1987 for Pu Kum district, and 0.5 per 1000 in 1988 for Nakhon Ratchasima Province). The size of the village is rather small compared with other Thai villages. The village is scattered over approximately 1 kilometre. There are 75 households with approximately 400 inhabitants. Houses are clustered together and are surrounded by flooded paddy fields. The village was established 120 years ago by four families who came from another village, one and a half kilometres west of Noan Pa. Like many communities in the developing world, all the forest and wild animals around Noan Pa have disappeared as a result of agriculture and human settlement. Increasingly fewer animals are caught for food. Villagers prefer hunting and foraging to spending money for food, but there is little left for them to forage or hunt.

The other 13 villages in this study are similar to Noan Pa village in terms of their ecological, social, economic, and cultural settings.

Socioeconomic Class

> *"A landlord is like a worm in faeces who does nothing but eat faeces until it gets fat."*
> (From an interview of a landless man in Noan Pa village)

In addition to changes in the ecological environment, Noan Pa village is also a peasant community experiencing rapid socioeconomic transformation, from a community of subsistence agriculture to one bound to a cash economy. The community embraces values that encourage individuals and their families to accumulate material goods that enhance social standing. Most villagers now pursue goals that urban or dominant classes have long enjoyed: education for their children, regular income, sturdy housing, sanitation, and electrical appliances.

The families of Noan Pa village can be classified into four social class strata (see Table 2): lower (poor/landless), lower-middle (somewhat poor), upper-middle (somewhat rich), and upper (landlord), distinctions recognized by the villagers themselves. When I first asked the village headman how many socioeconomic strata existed among the villagers, he identified four. I then asked the village headman and the former village headman independently to place every household into one of the four economic levels by comparing among themselves and ignoring the standards of other villages.

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[2]To protect the confidentiality of informants, the names of villages, districts, and individuals are pseudonyms.

Figure 1: Map of Thailand (*Source:* Reprinted from John L. S. Girling: *Thailand: Society and Politics*. Copyright (©) 1981 by Cornell University Press. Used by permission of the publisher.)

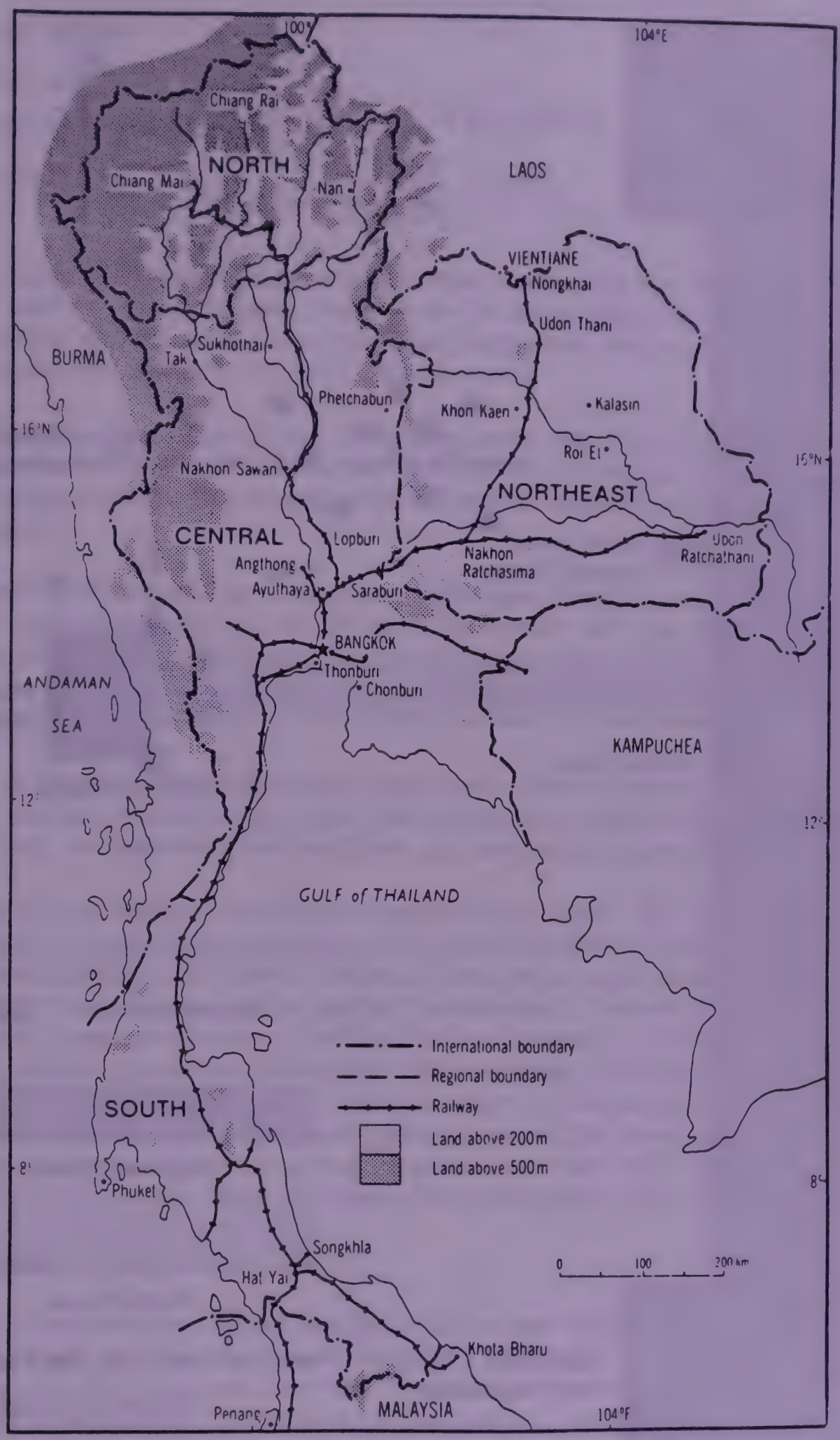

Figure 2: Map of Pu Kum Township

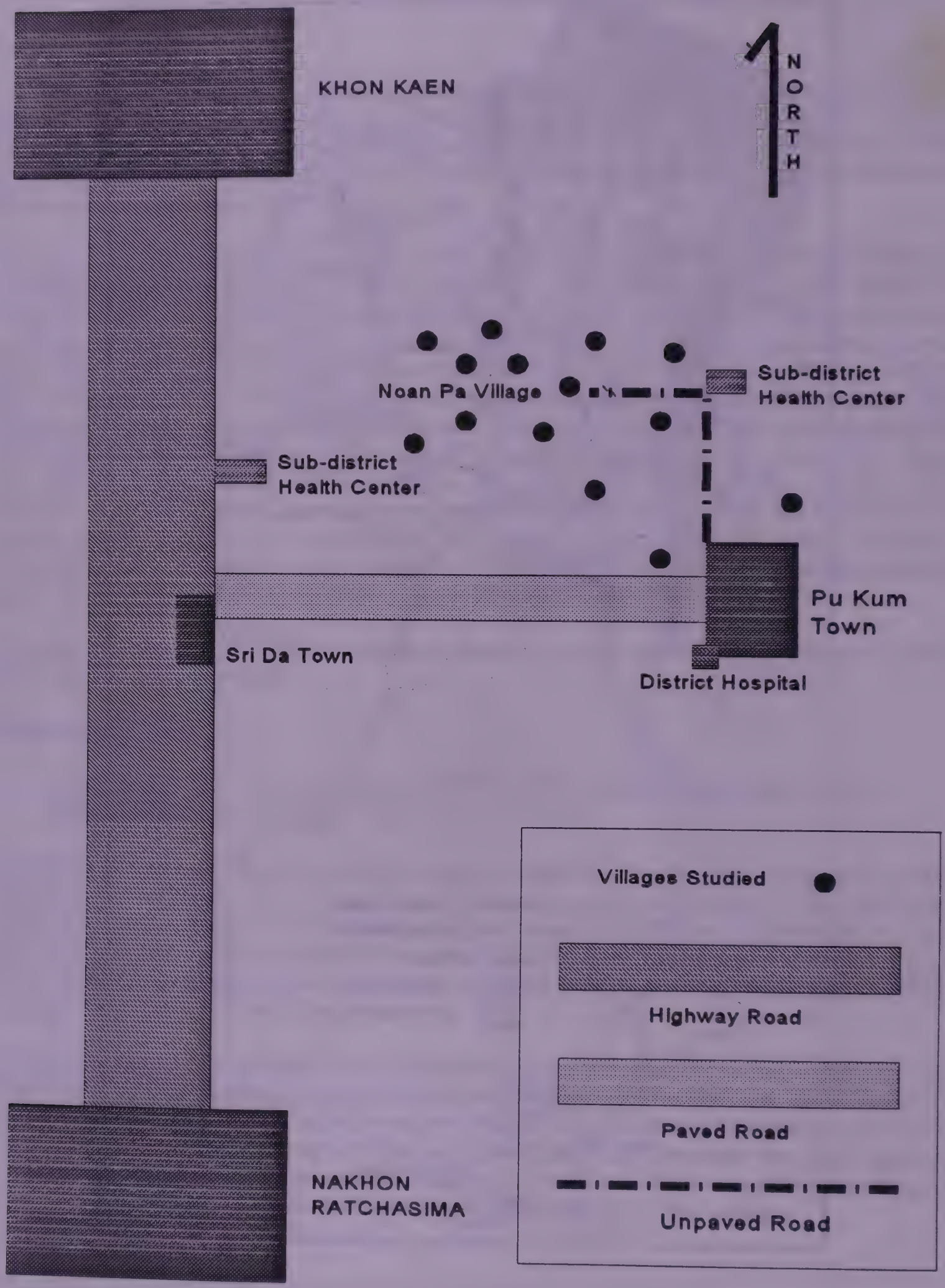

Table 2: Households by socioeconomic class

Class	Number of rai owned	Number of households	Percent
Lower (poor/landless)	0	23	30.7
Lower-middle (somewhat poor)	0–35	38	50.7
Upper-middle (somewhat rich)	22–90	9	12.0
Upper (landlord/rich)	0–270	5	6.6

The classifications of the two were generally the same, except in a few cases. In these discrepant instances, I used my own judgement, based on the following indicators: amount of land owned, lifestyle, housing, material goods (colour television, refrigerator, motorcycle, furniture), children's education, income and amount of rice crop gained per year.

About 31 per cent of the households are classified as lower class. These households live a hand-to-mouth existence. Most are landless and work as labourers for the landlords in their village during rice cultivation. Some choose to find seasonal agricultural work or wage labour in factories or construction sites in Bangkok.

Fifty percent of the households are in the lower-middle class. They are less poor compared with the first group. These households are mainly small landowners who can produce rice for family consumption for some months and must buy rice for the remainder of the year. Some are landless families whose children send money home regularly. Some are small shop owners who do not make much profit from their businesses.

Only about 12 per cent of the households are considered to be in the upper-middle class. They have ample food, well-constructed houses, and otherwise enjoy the comforts of life such as televisions or gas stoves. They are landowners who work their own land as well as rent land to the landless.

Five families (6.6 per cent) are regarded as being in the upper strata. They are wealthier than all the other households. Three families earn their living by renting land to others, working in their own fields, and teaching at the local school. The fourth family in the upper strata is the wealthiest in the village, earning its income by being a landlord, moneylender, ricelender, and merchant. The fifth family from the upper class does not have land, but both husband and wife are teachers and come from wealthy families. The wife is the daughter of the wealthiest man in the village. When her father dies, she will inherit a great deal of land. Wealthy villagers and landowners gain power, respect, and prestige in the community. Wealthy peasants always gain political power. Members of the village council are all drawn from those who are wealthy or have some land. None of the landless are elected to serve in the village council. Being poor means to be of low status and to be unrecognized socially.

Social Structure

The majority of households are nuclear families. A few are stem families or limited extended families, in which the parents stay with the youngest daughter's family or a daughter who recently married. Residence patterns are distinctively matrifocal clusters among households of female kin. The family system is what Sulamith Potter (1977) called "woman-centred," in which the network of ties between related women is a significant feature of the social structure. There are always close ties among sisters, and these families often reside near each other. Family alliance is also strong among parents

and children. There is at least one child who takes care of the old parents until death. For children who migrate to work in the cities, at least one child regularly sends money back to the parents.

Another important feature of the village's social structure is the neighbourhood. Villagers usually say that they are all related to each other (*phi nawng*, "siblings"), by which they mean that they all live within a community that has shared values and a shared destiny. The village is formally divided into seven neighbourhoods according to a village developmental project initiated in 1987 by the government. Each formal neighbourhood has from 7 to 19 households. A sense of relatedness does not develop among those in these formal neighbourhood structures, but it does develop among 3 or 4 households that live next to each other and are in the same class strata and kindred group. A neighbourhood group is also related through matriline because of the custom of matrilocal residence. Being neighbours raises clan consciousness. Neighbours support each other spiritually, materially, and socially. They exchange food, help in crisis situations (e.g. when someone has an illness), and take turns watching each other's children or house when someone is away. They often visit each other to chat. Gathering in one neighbour's house is another channel of communication through which village information flows.

Religion

In Noan Pa, as well as in the other villages in North-East Thailand, the entire population is Buddhist.[3] One of the most important religious ceremonies is the ordination of monks. In the religious ideology of the villagers, every man wants to be a monk at least once in his life. A three-month period of monkhood before marriage is the usual practice, and is considered to be the ideal minimum time to serve as a monk. The villagers believe that parents who arrange for their sons to be in the monkhood will earn the greatest merit[4] of all by this religious act.

Not every man can become a monk. Theravada Buddhist doctrine specifies the qualifications for priesthood. Excluded individuals include homosexuals; persons with five diseases considered to be contagious, chronic, and/or incurable (i.e. leprosy, smallpox, ringworm, epilepsy, and asthma); disabled persons (i.e. blind, deaf, or mute); persons with debt; persons who do not have parental consent to serve in the monkhood; slaves; and criminals (Grom Pra Ya Wachirayarnwarorot, 1991:101).

It is significant to note that, according to religious ideology, leprosy is contagious and incurable, and results from personal sin. Five monks whom I interviewed explained that a person who contracts leprosy and is subsequently "cured" by Western medicine is still not allowed to be a monk because the disease is considered uncured in the Buddhist sense. They also said that this prohibition cannot be changed because it was written by the Buddha himself. One portion of the written doctrine concerning leprosy is as follows:

> A person who cannot become a priest is the one who has a disease which is contagious, incurable, and chronic. These diseases are those among five diseases: *khut thung* ["*khut*

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[3]A few people from villages near Pu Kum town converted to Christianity. These were leprosy patients along with their families who had received treatment from missionaries and attended church activities.

[4]Merit (*boon*) is positive karma. One gains merit, among other means, through gift giving to the poor, the disabled, the less fortunate, and especially to monks and to the temple. A fund of accumulated merit will ensure a rebirth blessed with happiness, prosperity, and wealth. The greatest accumulated merit will lead a person to achieve salvation or final extinction (nirvana).

thung" literally means amputation of hands or feet]—leprosy, smallpox, ringworm, asthma or those with similar symptoms, and epilepsy. Before the monkhood ceremony is performed, the person must be asked whether he has one of these diseases. These diseases are the result of committing sin. (Grom Pra Ya Wachirayarnwarorot, 1991)

Local Medical System

Local health problems

Noan Pa is like many villages in developing countries with poor sanitation in terms of inadequate water supplies, lack of sanitary facilities, improper water and garbage disposal, faecal contamination of water and food, and unhygienic home environments. Every household in Noan Pa uses water from the same pond for bathing, household use, and sometimes, when rainwater is in short supply, for drinking (without boiling). The water pond could be contaminated by any of several kinds of infectious agents.

The villagers' most serious local health problems are infectious diseases and nutritional problems that result from poverty, poor sanitation, and certain cultural beliefs. The infectious diseases common in the village are diarrhoeal diseases, cold, flu, pneumonia, skin diseases (ringworm, chloasma, psoriasis, allergies, skin rash, and leprosy), and parasitic diseases (opisthorciasis, or liver fluke; *Necator americanus,* or hookworm; *Taenia solium,* or cestode; and *Enterobius vermicularis,* or threadworm). There are also a few cases of tuberculosis and venereal diseases. Some chronic urban illnesses also exist, including many cases of peptic ulcer, and a few cases of hypertension, diabetes, neurosis, and alcoholism.

Disease etiology and health practices

Most of the 56 villagers in Noan Pa understood the cause of local infectious diseases (e.g. the common cold, diarrhoeal disease, tuberculosis, and simple skin diseases such as chloasma and ringworm) in terms of folk concepts. Most villagers viewed the common cold as caused by a rapid change of temperature in the body (from hot to cold or from exposure to sun or rain). The person then develops a bodily temperature imbalance that causes him or her to catch cold. The predominant etiologic belief concerning diarrhoeal disease was that it is caused by eating foods that are poisoned, spoiled, too sour or spicy, or touched by flies. Most people believed that tuberculosis is caused by cigarette smoking and exposure to germs from nasal droplets. A simple skin disease is thought to be caused by the imbalance of wind and blood elements in the body, or the violation of a food taboo, or having bad hygiene habits such as not bathing often, wearing dirty clothes, or using a diseased person's clothes.

The villagers thus for the most part based their beliefs about what causes disease in a natural context (Foster & Anderson, 1978). Ascribing supernatural causes was usually reserved for cases of chronic illness had not been cured by Western medicine (i.e. treatment based on biomedical theories of disease), although not showing proper obeisance to a local spirit (e.g. not building a spirit house for the house spirit) was commonly believed to be one factor in the cause of illnesses that villagers were not familiar with. Among folk beliefs about disease causation, humoral theory predominated.

Humoral theory

Many signs and symptoms of illness are explained by the concept of *ruet lom mai dee* (the imbalance of blood and wind elements). These signs and symptoms of illness include skin diseases (allergy, skin

rash, ringworm, chloasma, leprosy, itching), fainting, headaches, and losing weight. Humoral theory[5] is predominant among the North-East Thai people and has its roots in Khmer-Brahmanical culture.

In Thai humoral theory, optimal health exists when all elements are in harmonious equilibrium with each other; illness arises when this normal equilibrium is altered. Illnesses that are caused by humoral imbalance occur under three conditions. The first is the increase of any one element in the body. For example, a woman who has delayed menstruation may suffer from headache, back pain, fainting, and fatigue. It is believed that the woman is accumulating too much blood in her body. The second condition involves the decrease of any of the bodily elements. For example, an old woman is believed to have less blood in her body, which can cause a skin rash and itching. A woman who has lost much blood during childbirth may suffer fainting, fatigue, and then weight loss or death. Finally, there is the condition that involves abnormalities of any of the bodily elements. A woman who eats certain kinds of foods, such as fermented bamboo (which is very sour), will have "bad" blood and develop a skin problem such as allergies or itching.

Humoral theory considers gender differences in explaining illness. Adult and elderly women are said to be more susceptible to the imbalance of blood and wind elements than men of the same age. Through menstruation, a young woman is regularly losing blood that is considered a "bad" or an excessive water element, and a woman's body therefore stays in balance. The irregularity of menstruation or menopause in advancing age can cause the imbalance of the water element in a woman's body. However, advancing age can cause the weakening of all four elements in both sexes. The weakening of all of the bodily elements causes a person to be more prone to all kinds of disease, including leprosy. Villagers believe that a person born into a family that has other family members with leprosy will develop leprosy when he or she becomes older because it is both inherited in the blood and triggered by humoral imbalance.

Eating certain types of food can cause an imbalance of the blood and wind elements. Those who consider themselves to be in this state will restrict the types of food they consume. To restore the balance of blood and wind elements, certain kinds of herbal medicines are used. For example, a boiled herbal drink is taken by women who have irregular menstruation.

Medical system

The term "medical system" is defined by Dunn (1976) as the pattern of social institutions and cultural traditions that evolves from deliberate behaviour to enhance health, whether or not the outcome of particular patterns of behaviour is improved health. In Noan Pa village, the medical system consists of several therapeutic sources, namely, traditional, cosmopolitan, private, and government healers. Multiple sources of care are normally utilized. The village has one herbalist, two magicians (the so-called *mao moan,* who use sacred water, magic spells, and betel-nut juice for curing), and a grandmother midwife, as well as seven village health volunteers who received Western training from

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[5]According to this theory, the human body is composed of four basic elements:

1. Earth (*din*): hard, static, and stable elements that are formed into the basic structure of the body such as hair, nails, teeth, skin, bones, nerves, the liver, the bladder, and so on.

2. Water (*narm*): elements that are liquid mediators, such as blood, sweat, tears, bile, urine.

3. Fire (*fai*): caloric elements that provide the body with warmth and aid digestion.

4. Wind (*lom*): elements of dynamic energy that initiate functions such as breathing.

the subdistrict health centre. Private local medical resources include three grocery stores in Noan Pa village that sell several Western drugs such as painkillers, cold remedies, medicine for diarrhoea, and antibiotics. In Pu Kum town, there are three or four private clinics where villagers go for treatment. Those who offer treatments in these clinics are not medical doctors but midwives, sanitarians, or nurses.

Leprosy Control Programme

Health care services for leprosy patients from Noan Pa village and other villages near Pu Kum town have included, and/or continue to include, the missionary mobile unit (between 1954 and 1959), the subdistrict health centre, the district hospital, the provincial Leprosy Zonal Centre at Nakhon Ratchasima, the leprosy mobile team (which visits the village twice a year), and the leprosy colony in Khon Kaen Province.

Prior to government involvement, missionary teams established stations in three villages near Pu Kum town for medically treating leprosy patients while simultaneously proselytizing for Christianity. Initially, leprosy was treated with injections of dapsone, which later was administered orally. Dapsone was prescribed to be taken once every seven days. The Christian missionaries' treatment of leprosy patients during 1954–1959 is well known among villagers in Pu Kum town. Those who developed symptoms of leprosy would travel to the missionary team to seek treatment. Travelling was difficult because it required walking for about two hours, so patients from Noan Pa and other villages did not receive treatment regularly. The cost of the treatment further inhibited the villagers from seeking it. The drug cost 2 baht or US$0.08 per visit, a significant amount for poor villagers, who usually have no cash in hand (in 1954–1959 the economy was largely subsistence, and the baht had greater value than at present).

Three to four years after the missionary station was established, the Zonal Leprosy Centre mobile team from Nakhon Ratchasima was set up to perform the tasks of case detection, case holding, and free treatment at the village level around Pu Kum town. The mobile team came to the villages in the Pu Kum town area twice a year.

Presently, although the leprosy control programme has been integrated into general health services, the leprosy mobile team still performs its tasks in the village because of the high prevalence rate of leprosy in the area. The team has recently expanded services for all types of skin diseases in order to destigmatize the process of coming for treatment. The team also provides education in self-care practices to prevent deformities, including demonstrating hand exercises to prevent contracture in paralyzed fingers, emphasizing the need to apply skin lotion or oil on the hands and feet to keep skin from cracking, checking for hand and foot ulcers every day, and treating small ulcers early, before they turn into serious wounds. Health education concerning self-care is given without continuing medical supplies and follow-up. This innovative measure is also limited to a small number of patients.

Distributing drugs is the only service provided to leprosy patients at the subdistrict health centre. One member of the health staff has had a special training course in diagnosis and treatment, but she had no confidence in her ability to make diagnoses independently. Although the health centre is only four kilometres from the village, no bus goes directly to the centre. The villagers from Noan Pa say they rarely go to the centre for treatment because it is hard to get to and provides low quality of care. Leprosy patients must visit the health centre once a month, however, in order to receive leprosy medication. This requires either an hour's walk, a 45-minute bicycle ride, or a 20-minute motorcycle ride. Once, when the bridge and road were damaged for several months during the rainy season, patients could not reach the centre to receive leprosy drugs.

The district hospital is available for leprosy diagnosis, treatment, and health education. The district hospital holds a leprosy clinic every Friday from 9:00 a.m. to 12:00 p.m. The clinic is staffed by an auxiliary midwife and medical doctors. Because the doctor had seen very few cases of leprosy, some early cases of leprosy had been misdiagnosed. Both the professional staff and the doctors show no obvious discrimination toward leprosy patients. However, the patients viewed the auxiliary midwife negatively because she was ill-tempered. She would often scold patients who came irregularly to receive leprosy drugs. Some nurse aides shunned leprosy patients and refused to treat their ulcers.

In summary, the medical care offered for leprosy patients in the communities studied is not yet fully accessible. As a result, many patients delay their initial treatment and have problems with drug compliance, which in turn results in high rates of deformity among patients.

CHAPTER 3

LEPROSY AND ITS MEDICAL SYSTEM

Local History of Leprosy and Social Responses to the Disease

Leprosy was first found to be endemic in the north-east region of Thailand in the early 1950s, a few years after the smallpox and yaws epidemics. In Noan Pa, since 1940, eight villagers with leprosy have died. Patients with white skin patches or small wounds that could be concealed stayed with their families and lived normal lives. Some patients who developed acute reactions or severe ulcers voluntarily isolated themselves, living in secluded rooms or separate huts. Severe sores were considered to be repulsive, more than merely a vehicle for the transmission of the disease. The patients' isolation was usually temporary, and after the acute condition improved, they returned to their families. Some, although very few, voluntarily isolated themselves permanently because of feelings of shame in relation to their neighbours. These were individuals with severe physical disfigurements and ulcers. However, isolation of patients was never complete, even for those who permanently lived in huts outside the village. Family members of patients still provided food for them. Patients came to the village to purchase items from the grocery shops, to gamble, or to ask villagers for food and money. Many villagers felt sympathy for poor patients and donated rice and money. There was no direct quarantine, even for the most severely deformed. Although the community viewed open sores as the primary source of transmission, most community members also believed leprosy was inherited, because the community often saw the locus of leprosy cases in one family line.

Leprosy Patients in Noan Pa Village

Government records of patients from 1991 show that 11 persons in Noan Pa were officially diagnosed as having leprosy and were registered as patients. Among these, one had died five years before the period of fieldwork. One female patient had moved to live in another province with her daughter's family. Among the remaining 9 patients, 4 had terminated their drug regimens four to five years previously. Of the 9 patients and ex-patients, 2 had developed claw hands and deformed feet. One had developed leonine facies and blindness and had lost all fingers and some toes. One had developed minor facial deformities. The remaining 5 developed no deformities, but had skin patches on their bodies that could be concealed by clothes.

Four of the 9 patients and ex-patients who still lived in the village were male and 5 were female, and they were all between 39 and 64 years of age. In terms of socioeconomic status, 5 of the 9 were landless and poor, 1 was in the lower-middle socioeconomic level, and the other 3 persons fell into the upper-middle socioeconomic level.

Their occupations were as follows: One female landless ex-patient without deformities earned her living as a wage labourer in the cornfields in another province. Two of the female landless ex-patients without deformities were tenants renting land from landlords in the village. One landless female patient who developed severe deformities stayed home and was financially supported by her daughter. One landless male patient with claw hands and deformed feet stopped travelling outside the village for wage labour work because of his visible deformities; he foraged for food, raised chickens for sale, and watched buffaloes in the harvesting season. One male patient who developed visible deformities on his hands and feet was a landlord who owned a small rice mill and rented out his land to three tenants. The other three persons, who developed skin patches only, worked in their own rice fields.

The nine patients and ex-patients in Noan Pa village were from eight kindred groups as follows (see Table 3):

Jam (#1, a 57-year-old woman): an ex-patient and her kin group. Jam suffered from the lepromatous type of leprosy. She underwent modern treatment over 34 years of irregular attendance.

She was finally discharged from treatment because she was regarded as cured in June 1991. Jam initially developed leprosy when she was 22 years old but had no treatment for ten years. However, from the villagers' point of view, Jam had not yet been cured of leprosy because her deformities, disabilities, and some ulcerations remained. She has leonine facies, no eyebrows, and has lost all fingers and all but two toes. Her left eye had become completely blind before I started my study. Her right eye became completely blind from trachoma by the fourth month of my fieldwork. The muscles under her eyes were distorted, and she was unable to close her eyes completely. As a result, dust got into her eyes easily and they were always red and itchy. Her eye infections often caused severe tearing, every three to five minutes, depending on the infection. She very often had minor ulcers on her hands and feet. Jam's name had became a synonym for leprosy in her village, and many villagers used her name when they spoke of the disease.

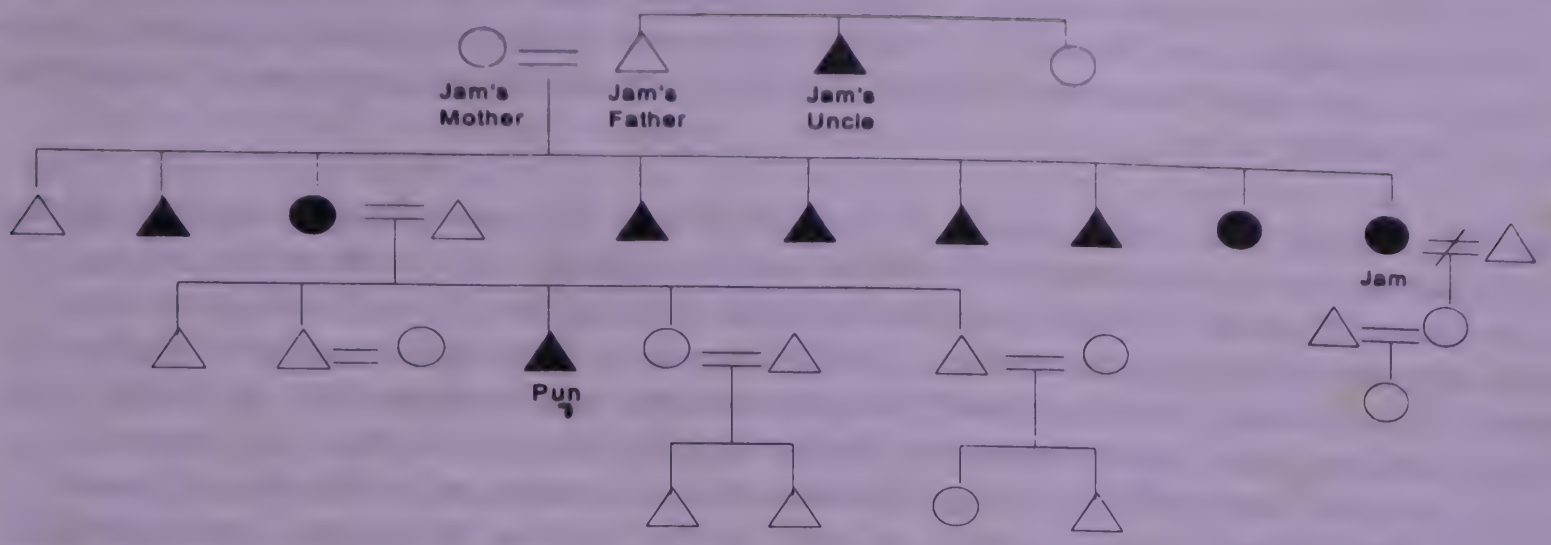
Jam's parents had nine children. All had leprosy except Jam's oldest brother, and lived together within the extended family all their lives. Jam's five leprosy-afflicted brothers suffered deformities of their hands and feet, and one was blind. They lost almost all their fingers and toes and developed chronic ulcers on their hands and feet. Her two sisters had developed white patches only and no visi-

Table 3: Details on leprosy patients and ex-patients in Noan Pa village

No.	Name	Date diagnosed	Age	Patient's status	Economic status	Deformity and disability
1	Mrs Jam*	1960	57	patient	poor/landless	leonine facies blindness no fingers loss of toes
2	Mr Jai	1967	64	patient	upper-middle/ landlord	claw hands deformed feet
3	Mr Yu	1974	60	ex-patient	poor/landless	eyes and mouth
4	Mrs Dok	1978	60	ex-patient	lower-middle/ tenant	none
5	Mr Pun*	1980	47	patient	poor/landless	claw hands deformed feet
6	Mrs Tim	1980	48	ex-patient	poor/landless	none
7	Mrs Chan	1980	59	patient	middle	none
8	Mrs Wun	1984	39	ex-patient	lower-middle	none
9	Mr Sa	1987	59	patient	middle	none

*Mrs Jam and Mr Pun are aunt and nephew.

Figure 3: A genealogy of Jam's family



Note: Filled symbols indicate persons with leprosy.

ble deformities. Jam had one daughter, who had no leprosy. Moe, Jam's older sister, married and had six children; two of them developed leprosy. One, named Pun, developed visible deformities on his hands and feet. He had claw hands and deformed feet and occasionally had open sores (see Figure 3).

Pun (#5, a 47-year-old man): a patient. Jam's nephew Pun has had a lepromatous type of leprosy since he was 28 years old. He did not receive treatment until seven years after contracting the disease. His hands and feet became deformed because his disease had already progressed before he began treatment, and he took the medicine irregularly. He lived in a very tiny house that was adapted from a rice container. He never married and lived by himself. His mother, sisters, and brothers moved to another province. He refused to follow his family because he considered himself deformed and ugly and feared being ostracized by villagers in the new village. His skin appeared very dark as a side–effect of the leprosy medicine. Most of the time he wore only a sarong or shorts without a shirt. If he did wear a shirt, it was very old and torn. He perspired heavily. Before he became deformed, he had travelled a great deal working as a labourer in several big cities. After developing claw hands and deformed feet, he stopped travelling outside the village. He foraged for food, raised chickens for sale, and was hired to watch buffaloes during the harvesting period or to saw lumber for his neighbour. He liked to gamble and joined the gambling and cock–fighting games at almost every match. He drank with the young male villagers who gambled, and did not socialize with any other villagers except gamblers.

Because several members of Jam's clan contracted leprosy, the belief that leprosy is a hereditary disease was formulated and reinforced among the Noan Pa villagers (see Figure 3).

Yu (#3, a 60-year-old man): an ex-patient. Yu suffered from the lepromatous type of leprosy. He developed his first symptoms when he was in his forties. He took medication regularly and was discharged from the drug regimen four years ago. He came from another village near Noan Pa. He married a woman named Wad, had eight daughters, and lived in a small hut made of bamboo and rice leaves with his wife, a daughter, and two granddaughters. He had contracted a venereal disease before the leprosy symptoms developed. His visible deformities included distortion of the muscles under his eyes and mouth. He could not completely close his eyes, and always wore sunglasses to conceal his deformed eyes and to protect his eyes from the sun when he went out of the house. His eyes became infected often, which caused them to tear. He could not see clearly when the sun was bright. Very few villagers recognized the abnormality of his eyes, but most recognized the deformity of his mouth.

His relationship with his family and other villagers remained normal, as these relationships were formed before he contracted leprosy. Villagers viewed his leprosy as a transformation from his previous venereal disease. No one discriminated against him because he showed no deformities on his hands or feet and he never developed any ulcerations. He and his wife were tenants working for a landlord in their village.

Jai (#2, a 64-year-old man): a patient. Jai suffered from a lepromatous type of leprosy and had undergone modern treatment irregularly since he was 36 years old. He was still on the drug regimen at the time of the study. He came from another district far away from Noan Pa village to marry his wife, Mee. He has six brothers and sisters. I was told by many villagers that one of his brothers had leprosy, but Jai denied that any other of his family members had the disease. He developed visible deformities, claw hands and deformed feet. He had very dark skin, a side-effect of the leprosy drug, and he perspired heavily. He lived in a large house made of wood, and owned 90 *rai* (1 *rai* = .4 acre) of rice fields and a small rice mill. Jai was a landlord and had three tenants renting his land. He lived with his wife and two grandchildren. Jai and his family ate together and never separated eating utensils. Jai never slept separately from his wife, even after he became sick.

Dok (#4, a 60-year-old woman), Tim (#6, a 48-year-old woman), Wun (#8, a 39-year-old woman, Sa (#9, a 59-year-old man), and Chan (#7, a 59-year-old woman). These were ex-patients and patients who had the tuberculoid type of leprosy and developed only white patches on their backs and arms. All started to develop their first symptoms in their thirties and forties. All except Sa and Chan took leprosy medication regularly for about seven years and were discharged. Sa never took his leprosy drug after being diagnosed with leprosy because he believed that he did not have leprosy. Chan took her leprosy drugs for only two months and then stopped. She stopped taking the drug because she was afraid of being ostracized if she continued travelling to the health centre to receive the leprosy medicine. Familial relationships and social relations with the community remained normal. Most of these five patients and ex-patients were very active in temple activities. Some cooked and brought food to the monks at the temple every day. Villagers were confused about whether these five people truly had leprosy because they never developed any disfigurement and no one in their families had had leprosy. Most people believed that Dok, Tim, Wun, Sa, and Chan only had a skin disease. Some believed that they might develop leprosy if they did not take leprosy drugs to "prevent" it.

Popular Beliefs Concerning the Etiology of Leprosy

The general population in the Noan Pa community and key informants from 13 other villages generally held four distinct views about the cause of leprosy: inheritance, violation of a food taboo, transformation of venereal disease into leprosy, and the imbalance of blood and wind elements.

During the community survey, the concept of disease contagion as the cause of leprosy was rarely mentioned. However, when specifically asked whether leprosy is contagious, most villagers agreed that it was. The majority of villagers believed that leprosy could be spread by touching patients' wounds and prolonged by personal contact such as eating, living, or sleeping with patients. However, many villagers, especially men, expressed the belief that a person who did not share the patients' same blood group (*sai lud douw khan*) would never contract leprosy, even though he or she might have had close contact with the patient. Most villagers believed that a person could contract leprosy through leprosy germs. They expressed the belief that there were *mae* (leprosy germs) in the patient's body that were excreted easily through open wounds, perspiration, saliva, and faeces. Touching the patient's body, eating or drinking with the patient, sitting where the patient had sat or bathed, wearing patient's clothes, and eating patient's chicken or pigs that had eaten the faeces of the patient all exposed a person to leprosy germs.

The concept of *mae* is similar to the folk concept of *kagaw* among the Tausug in the Philippines (Paz, Medina & Ventura, 1990:19). Leprophobia toward the family with multiple cases of leprosy was strong. Villagers believed that leprosy germs could be transmitted from this type of household by "jumping" from the patients' house to passers-by. Children also learned myths concerning disease contagion from their parents. For example, a person walking past a leprosy patient's house must loudly clear his or her throat so that the germs would be frightened and not jump onto that person. Folk beliefs about leprosy "germs" existed prior to the time that the biomedical model of leprosy was introduced by health workers through health education. The concepts of germs and the route of transmission via skin-to-skin contact have fitted well with existing folk beliefs. However, the term *mae* from the folk model differs from the conception of germs in the biomedical model. *Mae* in the folk model are small, animal-like organisms that exist in the patient's blood and come out from the body via several routes. Villagers believed in the rapid movement of *mae* from the patient's body or personal belongings to other persons. These beliefs reflect the cultural stereotype of leprosy as highly transmittable.

The term "low immunity" (*phum thaan thaan thum*) was also referred to by villagers. The idea of low immunity to explain why certain people are more susceptible to contracting leprosy had been introduced by leprosy health workers. In the biomedical model, low immunity refers to a measure of immune system competence. According to folk theory, immunity competence for leprosy is understood in terms of the quality of the person's skin. Villagers believed, for example, that babies or small children could easily contract the disease because they had very "soft skin" that leprosy germs could easily penetrate. In contrast, most villagers believed that adults had "hard skin" that resisted penetration by leprosy germs.

Popular Classification of Leprosy

In the community census on the popular classification of leprosy, most informants classified leprosy as falling into four stages. Perceived severity is critical for determining folk classification of leprosy.

1. White patches or spots (*rok ruan*, or leprosy)

Villagers referred to *rok ruan* as the skin disease characterized by symptoms of white patches or ringworm-like spots that sometimes itched. For those who were not born in families with histories of leprosy, the white patches were considered a skin disease that did not progress into leprosy unless the body underwent a humoral imbalance due to consuming certain food types. Folk beliefs based on humoral medicine are pervasive throughout Asia and Latin America. Illness and food are classified according to an etiological and therapeutic system that derive historically from Ayurvedic, Unani, Chinese, and Hippocratic humoral theories of disease (see Dunn, 1976:133–158; Golomb, 1985:128; Harwood, 1971:1153–8; Kay & Yoder, 1987:347–55; Kendall, 1987:367–76; Laderman, 1987:357–65; Manderson, 1987:329–30; Messer, 1987:339–46; Muecke, 1983:437; Nichter, 1987:377–87). If a person was born into a family with a history of leprosy and developed white skin patches, he or she would ultimately develop *khi thut* (leprosy, see item [3] below) the advanced stage of disease (characterized by physical disfigurement and ulcerations), unless he or she took leprosy medicine.

2. Nodules and thickening of the skin

This type of leprosy was less frequently mentioned than the other three types. However, most villagers believed that the person afflicted with leprosy could develop nodules on his or her face and thickening of the skin around the ear lobes, nose, and other facial parts.

3. Claw hands, ulcerations, and open wounds (*khi thut*)

Most villagers recognized leprosy only in the later stages of the disease when patients have visible deformities, which was referred to as *khi thut*. *Khi thut* is characterized by claw hands and open wounds on patients' bodies, especially on the hands and feet. This type of leprosy is believed to be the stage preceding the final stage of leprosy.

4. Lack of fingers and toes (*khut thung*)

Villagers believed this to be the final stage of leprosy. If the patient does not take leprosy medication, he or she will lose finger and toe bones. Villagers believed that the leprosy germs "eat up" (i.e. destroy) the fingers and toes.

While the merit of matching the Western biomedical classification of leprosy with the so-called popular classification of leprosy is arguable, for the purposes of this report it may be useful to demonstrate a relationship between these two systems of classification. North-East Thai terms and categories can generally be related to the Western five-group classification of leprosy (Ridley & Jopling, 1962) as follows: *Rok ruan* or skin disease, which is characterized by white patches or spots with numbness and loss of sensation around white patch areas (but with no other complications), is similar to tuberculoid (TT), borderline tuberculoid (BT), and mid-borderline (BB) leprosy. *Khi thut* is characterized by nodules and thickening of the skin, including symptoms such as leonine facies, ulceration, and claw hands. These symptoms are similar to the later stage of leprosy, lepromatous leprosy (LL), as characterized by Western biomedicine. *Khut thung* includes foot drop and lack of toes and fingers, which are also similar to deformities specified for LL and reactions in leprosy. Villagers do not regard neuritis, nerve damage, eye complications (such as acute inflammation of eyes and blindness), or other problems due to host cell-mediated immune response (e.g. high fever) as characteristic of the course of leprosy (for more details regarding medical aspects of leprosy, see Chapter 1).

Preventing Leprosy

Preventive measures for *khi thut* were valued highly by villagers. Because they believed that small children are very susceptible to contracting *khi thut*, they were particularly careful to keep children from close contact with patients. In a patient's family, a small child might be allowed to get near to the patient, but family members would not let the patient touch the child. Sharing clothing and washing patients' clothing together with clothing of nonpatients were avoided. Refusing to share meals or drink with a person afflicted with *khi thut* was strictly practised. However, within the family context, most family members, including little children, still ate together with the patient. Villagers avoided mingling with patients closely or for long periods of time, or marrying with descendants of leprosy patients. In the family context, small children slept apart from patients. For the spouse, the use of separate bedrooms was not reported except when a patient developed ulcers or reactions. Taking Western leprosy medication was believed to prevent *khi thut*. Preventive practices varied from person to person in terms of gender and economic class. More female than male, and more wealthy than poor, people tended to practise these preventive measures.

Folk Beliefs Concerning the Curability of Leprosy

> *"In the past, there was no cure for leprosy. The person who developed leprosy could only die of leprosy."* (From the oral history of one elderly villager)

Beliefs about the curability of leprosy affect what people who suspect they have leprosy decide to do about it. Patients' beliefs also affect their willingness to comply with drug regimens over a long period of time. And community beliefs about the curability of leprosy affect attitudes toward patients and the possibility of reintegrating them into the community. In the past, when there was no modern drug regimen, leprosy was viewed, and portrayed in Buddhist texts (Grompraya Wachirayarnwarorot, 1991), as an incurable disease. One famous folk-tale entitled "The 'Leper' and the Prophet" goes as follows:

> One day a "leper" travelled into a forest and met a prophet. The leper asked the prophet if he could cure his leprosy, and the prophet said he could. The prophet boiled herbs in a huge vat. While the water was boiling, he told the leper to jump into the vat. He promised the leper that he would help him out of the vat after he stayed in there a while and healed his leprosy. The leper was afraid to jump into the vat and asked the prophet to demonstrate it first. The prophet jumped into the boiling water without fear. The boiling water seared his skin off. The leper was frightened by the prophet's appearance and ran away without helping him out of the vat. The vat was too high for the prophet to get out by himself and he was boiled to death. Because he was so angry, before he died he placed a curse on all lepers: they would never be cured by any medicine and their skin would be ulcerated like his own burned skin. (From a story told by Sa, a patient, on 14 April 1991)

Stories such as this one lie at the root of villagers' beliefs concerning the incurability of leprosy. In Noan Pa village, 22 of 68 persons, or approximately one-third, stated that *khi thut* is an incurable disease. What is meant by "incurable" in the villagers' view is the persistence of *khi thut* symptoms, such as disfigurement, ulcerations, and scars on ex-patients' bodies. Villagers also believed that a "relapse" might occur if ex-patients violated food taboos. Other informants explained that if patients took leprosy drugs early and regularly, deformity would be prevented and leprosy could be cured.

Health Practices for Leprosy and Popular Views on Multidrug Therapy

In the past, people regarded leprosy as among the most life-threatening of diseases. They evolved their own folk-healing medicine, based on plants, long before modern medicine was introduced to their communities. Surprisingly, they did not look to supernatural causes of leprosy, nor did they rely on supernatural remedies as did other societies such as the Tausug in the Philippines (Paz, Medina & Ventura, 1990) or the Hausa in Nigeria (Shiloh, 1965). The oral histories reveal that older patients sought treatment from herbal doctors but not from other traditional healers such as exorcists, monk doctors, or spirit mediums. This may be explained by the fact that the causes of leprosy were believed to be well known.

Before dapsone, Thai people who suspected they had leprosy sought help from traditional healers, who often prescribed chaulmoogra nuts. The nuts were crushed, and two to three spoons of crushed nuts or a whole plant was boiled and taken daily. All patients took this herb for a long period of time, one to ten years. Treatment seldom resulted in cure, so many patients of the older generation had claw hands or missing fingers. All of the researcher's informants who are in the age range of 50–80 years old (11 of 54 patients and ex-patients) and who developed the disease before dapsone was discovered, had used herbal medicine as a cure for leprosy.

After the leprosy control programme in Nakhon Ratchasima was implemented by missionary organizations and the Thai government in 1959, the general population, as well as leprosy patients, became aware of Western drug treatments for leprosy. They had high hopes for the effectiveness of Western leprosy drug treatment, and expected that it would be far superior to traditional methods. Ultimately, they thought leprosy would be cured by Western drugs.

From the interviews of 54 patients and ex-patients about their health-seeking behaviour, it is clear that most informants did not proceed through the different stages of health-seeking behaviour that are normally associated with the Thai, who tend to use multiple sources of care in a hierarchical behavioural pattern approach (see Cunningham, 1970; Hongvivatana & Hoontrakol, 1982; Rauyajin et al., 1981; Riley & Sermsri, 1974 for more detailed discussion). People who developed white skin patches lived in fear that they might have contracted leprosy and were concerned about community ostracism that would result should they attempt to seek treatment. At the same time, they were afraid that if they did not seek treatment, the leprosy would grow worse, until ulcers and bodily disfigurement developed, thus definitely resulting in shunning by the community. Because of the belief in the efficacy of modern drugs provided by well-known, available treatment sources (e.g. missionary mobile stations, the provincial Leprosy Zonal Centre, and mobile leprosy clinics that regularly came to the village), most informants did not "shop around" for alternative sources of treatment, as they would with other chronic diseases. They were willing to spend a few hours travel time to receive treatment from these well-known sources. The process of destigmatization was initiated by the mobile team leprosy workers, who later emphasized their services as a skin clinic that covered treatment for all types of skin diseases. They encouraged patients to overcome fear of stigma by telling others that treatment was sought for a simple "skin disease."

Most of the study informants (40/54 informants) had received their first treatment from the mobile leprosy team in their villages and continued to receive leprosy drugs from the subdistrict health centre. Ten out of 54 informants (in the age range of 50–80 years old) started their first stage of health-care seeking by treating themselves with herbal medicine, since they developed leprosy prior to the discovery of dapsone and the implementation of the leprosy control programme. Six out of 54 informants sought their initial treatment from the missionary mobile unit. These were the people who became ill prior to the implementation of the government leprosy mobile team. Twelve out of 54 informants sought their first treatment from government health services, which include the Zonal Leprosy Centre, Leprosy Colony, district hospital, subdistrict health centre, and Zonal Venereal Disease Centre. Only 4 out of 54 informants went to a private clinic as their first treatment source. Only a few informants practised self-medication (purchasing Western medicine for skin diseases) as their first stage of treatment.

In 1986 monodrug therapy (dapsone) in the government leprosy control programme was replaced by multidrug therapy (MDT) for leprosy treatment in the study area. MDT consists of a combination of dapsone, rifampicin, and clofazimine that is more effective than dapsone alone because it helps to prevent dapsone resistance. MDT also kills *M.leprae* much more rapidly than dapsone alone. WHO has pointed out that after taking a single dose of 600 or 1500 mg of rifampicin for a few days, 99 per cent of *M.leprae* is destroyed (WHO, 1988). Nevertheless, villagers from Noan Pa and the other 13 villages studied lacked knowledge about the recent change in the leprosy drug regimen. The general population had never heard of the newer multidrug therapy. However, many nonpatients from the study community were familiar with dapsone and referred to it as the "small white drug" or the "foreign drug." The "foreign drug" was believed to be very powerful and capable of curing leprosy, provided the patient started the drug early and took it regularly for a prescribed period of time. Beliefs in dapsone's effectiveness existed among the general population despite the fact that no one had had experience with a patient completely cured with dapsone.

In contrast to the general population, leprosy patients were quite knowledgeable about both mono- and multidrug therapies. They also placed a high value on Western medicines, especially MDT. In the past, however, patients had viewed monodrug therapy as ineffective because they did not see rapid improvement following administration of the medication. Once MDT replaced dapsone, patients tended to view MDT as being much more powerful than dapsone alone. Patients were told by leprosy health workers that MDT medicines were "good" and "expensive" drugs, and that the disease could be cured in only six months to two years by taking these new drugs. Leprosy health workers chose a health education message that they thought would be short, easily understandable, and convincing to the villagers. Although the message lacked details about the differences between MDT and dapsone, the possibility of a cure in a short period of time motivated patients to take the drug regularly and consistently.

The portrayal of MDT by leprosy health workers as a superior Western drug also contributed to patients' understanding of their physical condition after taking MDT. Several patients shared common experiences following MDT administration. Their urine turned red (a side-effect of rifampicin), which they understood as the medicine expelling the leprosy germs from their bodies. They reported a floating feeling within their bodies. (According to the popular view, a floating or light feeling within the body indicates a healthy condition. In contrast, when they took dapsone, they felt heavy inside, indicating an unhealthy condition.) They also felt that the medicine decreased perspiration, which reduced unpleasant odour. It was believed that taking MDT helped prevent serious ulcers, and that ulcers could heal more rapidly. Patients held these beliefs in the positive effects of MDT despite the fact that, empirically, not all of the expected benefits were obtained. In any case, by taking MDT, patients developed a more positive self-image and less self-stigmatization.

Although MDT has proved to be effective because it works faster and does not cause drug resistance, MDT does not improve the condition of sympathetic nerves (nerves that produce perspiration) and glands that are already functioning abnormally. So MDT does not alleviate patients' heavy perspiration. MDT is also not effective against other bacteria that cause secondary ulcers, so MDT does not help to prevent further infection in patients' ulcers, nor does it help in healing the ulcers more rapidly. It is significant, however, that patients perceived some benefits from taking MDT. Their perceptions also give an indication of the enormous power and authority of the medical profession to control medical knowledge (Freidson, 1970; Foucault, 1980).

CHAPTER 4

SOCIAL AND CULTURAL CONSTRUCTIONS OF THE STIGMA OF LEPROSY

Extent and Forms of the Stigma of Leprosy

In his classic work *Stigma: Notes on the Management of Spoiled Identity*, Goffman (1963) defines stigma as an attribute, an undesired "differentness" that discredits or disqualifies the individual from full social acceptance. He suggests that only through social intercourse do these attributes have the potential to create discrepancies in social identities, discrepancies in which a person's identity becomes synonymous with stigma. However, social intercourse among the Thai is based on "ubiquitous affability" and politeness, characterized by the technique of avoidance of social conflict in direct social contact (Phillips, 1965). The notion of social etiquette in Thai society, what is allowed to be expressed and not expressed, or said and not said, is embedded in the norms of social intercourse. Thus Goffman's idea of stigma cannot be applied loosely. As illustrated below, the behavioural manifestations of stigmatization directed toward leprosy patients among the villagers studied differ from the expressed ideology concerning the stigma of leprosy.

Ideology of leprosy stigma

Villagers recognized leprosy only in the late stages of the disease when patients have visible deformities, referred to as *khi thut*. The general population believed that *khi thut* is a "disgusting" disease and that the person with *khi thut* should be excluded from any social activities. Villagers often referred to leprosy as *rok sungkhom rungkhiat,* "the disease of social loathing." Leprosy is the only disease in Noan Pa village, as well as other parts of Thailand, that is labelled as a disease requiring social ostracism. Most villagers feared *khi thut*, and some people believed it to be highly contagious. Community members held that patients with obvious bodily disfigurement should be prohibited from joining social activities, and they preferred to see these types of patients confined to their own residences or leprosy colonies so as to avoid encountering their disfigurement. Villagers did not want to eat or drink with patients, and they similarly wished to avoid the area where a patient had sat or walked. Villagers had rules that a person with *khi thut* was expected to follow. These rules included restricting oneself to one's own house and not socializing with or visiting other villagers (if it was necessary for patients to visit other villagers' houses, they should not stay long); forbidding patients to obtain water from the well; and forbidding patients to greet villagers' guests or join any social functions.

Behavioural manifestations of stigma

In terms of the actual behaviour directed toward leprosy patients, those with skin patches only were not ostracized by the community because they were not viewed as having *khi thut,* but merely a "simple skin disease." The level of social contact depended on the degree of visibility and severity of the symptoms. Villagers had normal social relations with such patients, eating and drinking with them without developing repulsion or ostracism. As one informant stated, "Although I know that those who developed white patches on their skin have an early stage of leprosy, I do not feel repulsed by them because they have no sign of *khi thut*, no sign of claw hands and feet, no leaking ulcers." Patients who had red nodules and thickening of the skin were viewed as having contracted an early stage of *khi thut* and were mildly ostracized. Villagers felt somewhat disgusted by such patients but still retained most social contact with them.

The ideology of leprosy stigma caused villagers to prefer that those patients with *khi thut* or visible hand and foot deformities be excluded from normal social activities or even from the community. However,

the stigmatizing behaviour on the part of the community directed toward patients with *khi thut* was not expressed to the same degree as the held ideology. All community members appeared to tolerate leprosy patients with bodily disfigurements without any visible attempt to expel them from the village. Some villagers maintained some social contact with these patients, such as conversing, gambling, and drinking with them. Many provided financial support and food to disadvantaged leprosy patients.

In general, the discrimination of community members toward patients in daily life was not displayed directly, in face-to-face social interactions. If patients violated the expected rules, Noan Pa community members usually tolerated this "inappropriate behaviour," for example, when a patient sat on the chair instead of on the floor, sat close to another villager, or shared a glass with other villagers. Villagers usually did not directly criticize or prohibit patients directly from engaging in such behaviour.

However, most villagers' ostracism was usually communicated in a culturally acceptable way. Discrimination and social sanctions arising within the community were usually in the form of gossip and talking behind patients' backs. It was considered unacceptable among community members to tell patients directly that they were excluded. As one landless women said: "I don't like the way Jam spits her betel-nut juice on the ground because I am afraid my small children will contract the disease by swallowing the soil contaminated with her saliva. But I dare not criticize her. How could I? We are all human beings. If I scold her, others will scold me. I just find a little cup for her to spit her betel-nut juices."

Still, all patients were aware of the discrimination and had experienced social ostracism from the community. The gossip about leprosy patients often came back to them. Or close neighbours or relatives would inform patients about the repulsion that some villagers felt toward them. These communication channels were also mechanisms for social control and sanctions for excluding patients from social activities. As one informant who is Jam's daughter told me: "I never cook food for the monks, for I know monks and my neighbours will not eat it. My neighbour told me that Orn, the wife of the village headman assistant, who is very active in preparing food for the monks, said that she is not going to accept any food from my family because my family is a *khi thut*'s family." Patients also saw how other patients were criticized by the community.

So in contrast to Goffman's premise, the stigma of leprosy in the Noan Pa community is not formed through direct interactional processes. Rather, it predominantly arises through the process of indirect, ongoing social gossip and backbiting in which the social disqualification of being a person with *khi thut* is given social meaning. This creates discrepancies in social identities, discrepancies in which identity becomes synonymous with stigma. The stigma of leprosy assigns an individual identity associated with social ostracism, exclusion, and shunning.

Self-stigma

Leprosy patients held the same ideology toward their disease as did other community members. Those who had obvious disfigurement withdrew from most social activities, including becoming monks, participating in temple ceremonies, giving food to monks, taking water from the pond, eating or drinking together with nonpatients, attending social feasts and village meetings, and so on. When patients visited neighbours, they knew they were expected to sit on the ground rather than on a chair, and to leave some distance between themselves and other people.

Self-stigmatization caused a certain degree of psychological distress, low self-esteem, and social withdrawal, as evidenced by such phenomena as suicidal thoughts and no social activity with neighbours. Patients with visible disfigurement withdrew from most social activities because they did not want villagers to be repulsed. They viewed themselves as being unclean, impure, polluted, and sinful.

Producing the Stigma of Leprosy: Body, Pollution, and Danger

As noted earlier, Goffman (1963) describes stigma as an attribute that is deeply discrediting, a process that reduces the possessor from a whole and "normal" person to one who is tainted and discounted. From the villagers' point of view, conditions that elicit extreme repulsion include blood and pus from open wounds, disfigurement of the hands and feet (i.e. claw hands and feet, lack of fingers and toes), and the unpleasant odour from wounds and excess perspiration. Yet it is argued that it is the cultural and societal meanings ascribed to these attributes of the leprosy patient's body, and not the attributes themselves, that define the repulsive body images.

According to the popular view, leprosy's incurability made the disease both mysterious and frightening. People's views on *khi thut* were thus symbolically constructed in a manner that emphasized contagion and resulted in shunning of people with the disease. Susan Sontag writes that "any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious....Contact with someone afflicted with a disease regarded as a mysterious malevolence inevitably feels like a trespass, worse, like a violation of a taboo" (Sontag, 1979:5-6).

Physical maladies, such as the presence of bodily fluids and excess perspiration from patients' bodies, relate to the villagers' concepts of pollution and danger. Mary Douglas states, "Our idea of dirt is the result of contact with 'dirt.' And our idea of dirt is dominated by the knowledge of pathogenic organisms" (Douglas, 1966:35). Blood and pus are symbolically viewed as dirty and the carriers of pollution from the afflicted body. Coming into contact with blood and pus is like coming into contact with a corpse, which conveys the image of unclean "marks," transmission, and danger. As one villager told me, "A person with leprosy is much more disgusting than the person with AIDS because he has ulcers and sores which are full of blood and pus. They smell very strong. No one wants to stay near the leprosy patient because he or she may transmit leprosy germs through blood or pus from his wound or open sores."

Etiologic beliefs concerning leprosy reflect the concept of pollution. The belief that leprosy is a transformation of a venereal disease, which in turn is associated with promiscuous behaviour, reflects the notion that leprosy is an unclean disease.

John Janzen (quoted in Scheper-Hughes & Lock, 1987:20) writes, "Every society possesses a Utopian conception of health." In rural Thai society, the idea of good health is based on the humoral theory—the balance, harmony, and integration of four elements in a person's body. Something that interferes with balance and harmony is abnormal, and one way of dealing with abnormal events or elements is to label them dangerous. Thus, the bodily fluids from the patients are considered disordered, dirty, and dangerous. One of my informants said: "Leprosy germs come out of the patient's body and spread to others through the blood and pus from his open wounds as well as his sweat."

Edward Jones and other psychologists (Jones et al., 1984) who study the psychology of "marked" relationships state that aesthetic qualities have the potential to influence stigma. Some apparently moral judgements attached to disease are really aesthetic judgements about beauty and ugliness as well as cleanliness and uncleanliness (Sontag, 1989:41). Every culture has its own standard of beauty, but in general, every culture values body symmetry and the control of bodily fluids (Boutte, 1987:15). Claw hands, deformed feet, and open wounds with pus are perceived as repulsive, ugly, or upsetting conditions that cause people to avoid looking at or being close to patients. Excess perspiration and the discharge of blood and pus from open wounds show a lack of control of patients' bodily fluids, which in turn elicits people's avoidance and rejection.

Leprosy carries an especially heavy stigma because the patient's body is viewed as deteriorating over time (Jones et al., 1984). In fact, in the past in rural areas where effective treatment was not available, leprosy progressed and became more debilitating over a number of years. The most seriously affected patients experienced the loss of fingers and toes, blindness, and deformity of the face and nose.

In Thai society a person is expected to act within the context of a strict social hierarchical order, such as that between a father and son, an adult and child, or even between the rich and poor. Most of those afflicted with deformities were poor peasants who always dressed in old, torn, dusty clothes. Body appearance, physical disfigurement, ulcerations, excess perspiration, and an unpleasant odour are considered to be symbols of moral pollution and dirt. The sense of pollution carried by the patient thus is directly related to the fact that the patient is of a lower social class. The concept that certain body images are considered disgusting is further reinforced when leprosy prominently afflicts the members of society who are already marginalized by their socioeconomic status. As one landless peasant stated: "Pun [a landless patient] is usually dirty and smelly because he is too lazy to bathe or launder his clothes, and he has no regard for his appearance. I felt disgusted by his dirtiness and bad smell. He is not like Jai [a wealthy patient who has the same disfigurement as Pun], who looks much cleaner than Pun."

Reproducing the Stigma of Leprosy

Everyday use of language

Edward Sapir has commented that "language is a guide to social reality," whereas Benjamin Lee Whorf has observed that language patterns and cultural norms "grow up together, constantly influencing each other" (Sapir & Whorf, quoted in Leap, 1990:137). If we examine the language and the manner in which villagers talk about leprosy, we can discover the various labels people assign to the disease. Nonneutral discourse surrounds the daily usage of words associated with leprosy, and there are several notions embedded in the term "leprosy."

Dirtiness. Villagers always used the term *khi thut* when they wanted to refer to leprosy. *Khi*, which is a prefix when used with another word, means bodily excretion (for example, *khimuuk* means mucus, *khikrai* means skin scurf, *khihuu* means earwax). *Khi* is also used as a prefix of words that convey a negative connotation (i.e. *khikhait* means lazy, *khireaw* means ugly, *khihung* means jealous). *Khi* literally means "faeces," which villagers consider to be dirty. Thus, some informants avoided using the full term *khi thut*, preferring to use the word *thut* only. The word *thut* itself means leprosy—the disease that causes the loss of fingers and toes and ulceration. They explained that using the word *khi* sounded impolite to them. So the notion of dirtiness is embedded in the name of the disease.

Disfigurement. Villagers often used the elaborate expression *khi thut khut thung* when they wanted to refer to leprosy. The term *khut thung* literally means the lack, or shortening, of fingers and toes. The use of language to label leprosy always carried stereotypical meanings of disease implying disfigurement.

Social ostracism. Villagers, including patients, often used the term *rok sungkhom rungkhiat* ("the disease of social loathing") to refer to leprosy. The term was introduced by the leprosy health workers, and it has become the dominant term and concept. Leprosy is the only disease in the community that is classified as a disease of social loathing.

Incurability. Some villagers used the term *rok yai* (the great disease) when they wanted to say leprosy. From the emic point of view, *rok yai* means the disease that has no outside cure. People will either die or be cured of the disease, depending on their fate.

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Naming the unnameable. People who had developed certain symptoms of various skin diseases usually felt uncomfortable using the word *khi thut*. They avoided naming the disease as *khi thut*, and instead used the term *rok nuew nun* (that kind of disease). The avoidance in using certain words implies that there is something wrong in using, or negative about, those words. When villagers were asked why they avoided using the name of the disease when talking about leprosy, they answered that the word itself sounded dirty and impolite.

Contagion. In their everyday conversations, villagers constantly used expressions, jokes, and idioms that portrayed leprosy as a highly contagious disease. Everyday joking about the contagion of leprosy is an indirect way of releasing anxiety about contracting leprosy from the patients with whom they must have daily contact. These popular daily uses of language included the following:

"Don't let Jai [the patient with the disfigurement] drink with us; his glass is contaminated by his disease."

"I do not want to catch any fish from the pond Jai uses. After he has been in the pond to catch the fish, I am more afraid to contract leprosy from him."

"They burned the dead body of the patient because the fire will destroy all the leprosy germs. If we just bury the dead body, the leprosy germs just stay right there. We burn the patient's corpse to kill the leprosy germs."

One day while I chatted with teenagers, one boy told the following: "Jai teased Ram by pulling his ear. Ram had to hurry home and wash it right away because he was afraid of contracting the disease." After the story ended, everyone laughed.

These statements reflect the ideology of the stigma associated with leprosy, that it is filthy, contagious, mysterious, and to be avoided. Language gave villagers an indirect way of releasing stress about their fear of leprosy and aversion toward the disease. But the words villagers used to talk about leprosy also perpetuated the stigma attached to the illness.

Socialization

> One day, I [researcher] came home to Bangkok from my fieldwork. My daughter greeted and saluted me by making her hands in claw shape. She said to me, "Hello, Mother. Grandma told me that you went to interview the person with *rok ruan*. She also told me to greet you with the hands like this. This is the way that the person with *rok ruan* looks, is that right, Mother?"...Now I realize my daughter has been taught the stereotype of leprosy. (From field notes of 6 May 1991)

Unlike Goffman, Becker & Arnold (1986) argue that the major origins of the experience of stigma for individuals come from social attitudes that are both discriminating and widespread in the society. The ideology of stigma is produced and reproduced by processes of socialization associated with family, schools, and the mass media. For example, children are socialized by their parents to internalize negative attitudes about certain stigmas. This is also the case in my study. Children in Noan Pa village were taught by their parents not to go near a person with *khi thut* because they would contract the disease. Some parents had seriously threatened their children, saying that *khi thut* germs were highly contagious and that the children should avoid the patients as much as possible.

When children go to school, they are again taught the cultural stereotype of leprosy. One informant said her teacher taught the students that leprosy was the disease causing the most social ostracism. In the past, health educators had noted the cultural belief concerning leprosy as a disease of social ostracism

and placed this notion in the educational material ("leprosy—the disease of social loathing") in order to convince patients with leprosy to seek early treatment and maintain regular drug intake. Health educators also tried to convince patients to seek early treatment by showing photographs of severe ulcers in slides or pamphlets concerning leprosy signs and symptoms. However, these photographs aroused aversion and fear among most of the people who saw them. As a result, some government health education messages reinforced the social loathing of leprosy among community members.

Leprosy and its metaphor

All societies are forced to deal with two aspects of disease pathology: one that involves disease as the "disease" (biomedical) and another that involves disease as the "illness" (social and cultural construction) (Kleinman, Eisenberg & Good, 1978). Sontag (1979) has stated that, although the signs and symptoms of sickness have biological characteristics, they always carry a second layer of reality expressed in cultural images and metaphors. Leprosy as illness incorporates judgements about its meaning for sufferers and society, judgements that are culturally specific and received through the medium of metaphor. In the community studied, leprosy has given rise to another pathogenic process, the production of a socially destructive illness metaphor. The word for leprosy (*khi thut*) conveys the other meanings of the sickness, namely, that it is contagious, unclean, debilitating, disgusting, immoral, and a cause for social ostracism. Thus, leprosy is an illness that is socially and culturally constructed.

This metaphor of leprosy was portrayed in daily conversation among villagers and reinforced the persistence of the stigma of leprosy. Several times while I lived in the village, villagers made jokes by using the name of Jam, the most severely disfigured patient (who has leonine facies, no fingers, loss of toes, blindness), to represent characteristics of skin patches or skin diseases seen on people or on animals. People also used her name several times instead of saying "*khi thut*."

Stigma of leprosy in the Buddhist context

According to Buddhist belief, leprosy is a disease that is contagious and incurable. A man with leprosy is not allowed to enter monkhood because he is assumed to have bodily disfigurement. The illness disqualifies him from becoming a monk, one who is regarded with high respect from the people. It is assumed that allowing a person with leprosy to join the monkhood would spread the disease to other monks, because all monks share meals and drinking water as well as engage in other close social contact such as chanting or living together in the same temple. According to Buddhist doctrine, a person with leprosy suffers from the disease as a result of sinful acts committed during the previous life and is thus viewed as sinful and immoral.

To the villagers, the Buddhist notion of leprosy has emotive power in other ways as well. So rare is severe disfigurement in the normal population that a leprosy patient was viewed by the community as a person who developed the disease and disfigurement as a result of performing a grave act of demerit (*baap*), such as homicide. Some informants used notions of karma and *baap* to explain the cause of their leprosy as well. They felt they endured suffering during this life as a result of immoral actions in a past life, and sought a better life after death (i.e. one without disease) by performing good acts.

Thus, the Buddhist conception of leprosy as a consequence of immoral and sinful acts still influences villagers' beliefs and leprosy patients' self-stigmatization. But it would be wrong to conclude that the social definition of a leprosy patient as immoral or sinful directly leads to the patient being shunned by others. The manner in which some people behave toward patients is also influenced by the Buddhist notion of compassion (*metta*), and the value of performing merciful acts toward those who suffer or are inferior. To provide a sufferer with material and social support allows a person to accumulate merit (*boon*) in the next life. Based on this competing ideology, villagers hesitate to show social rejection

directly to the patient, and some also provide material and social support. This humanistic ideology is more prominent among the poor than the rich.

Social etiquette of Thai culture

Behavioural manifestations associated with the stigma of leprosy were not as strong as leprosy stigma would lead one to expect. To understand this phenomenon, we need to take into account the notion of "social etiquette" in interpersonal relations among Thai. The code of appropriate behaviour among the Thai is governed by such norms as "ubiquitous politeness" (Phillips, 1967) and the concept of *kreng chai* (Moore, 1974:183). *Kreng chai* refers to the desire to be self-effacing, respectful, humble, and extremely considerate, as well as the wish to avoid embarrassing other people, not to intrude on them, or cause them to extend or trouble themselves. The ideology of gentleness and *kreng chai* can be used to explain the apparent lack of strong ostracism in people's interactions with patients. Although a person might be annoyed when leprosy patients did not follow the expected rules or worried that children might contract leprosy from patients who are allowed to stay around the house, most people did not directly express condemnation to patients. The villagers followed the cultural code of behaviour by being friendly, pleasant, and polite with patients at a certain level.

The avoidance of direct expression of ostracism allowed people with *khi thut* to be accepted in the community, and to maintain some social contacts with certain groups of people. However, strictly speaking, the practice varied according to social class. Wealthy villagers or village leaders would not hesitate to show direct ostracism of poor patients.

Stigmatization within the health care system

Health practitioners hold power over patients because of their knowledge and skill. The importance of labels assigned to any identifiable entity becomes particularly important if the labels are given by persons in positions of authority. Health professionals can either foster or reverse a process that leads to potential exclusion of people from the community.

Health care workers as destigmatizers. Goffman used the term "the wise" to describe people who do not themselves carry a stigmatizing trait but who are exceptionally knowledgeable and have an empathic understanding of the stigmatized (Goffman, quoted in Volinn, 1983). The "wise" sometimes tend to overemphasize their role as friends and advocates and become destigmatizers (Volinn, 1983:389). Leprosy health workers from the Zonal Leprosy Centre, mobile skin clinic, leprosy colony, district health centre and missionaries all held humanistic values and devoted time and effort to serving leprosy patients. The roles of these health workers as destigmatizers were as follows: they expanded the leprosy mobile team services to provide treatment for other skin conditions, which served to lessen the tendency to define those seeking treatment as persons with leprosy; they provided accurate information to the communities that leprosy is curable if patients take medication regularly; they concealed the diagnosis of several patients and used the term "skin disease" rather than "leprosy" when mentioning the patients' disease to patients' relatives or neighbours; and some health workers treated the patients with courtesy and showed by their manner that they did not shun them (e.g. they touched the patients' bodies as well as treated ulcerations without any fear or aversion; they made regular home visits to bring leprosy drugs).

Health care workers as a stigmatizers. Health care providers from the general health service system who had little experience with leprosy cases tended to display more ostracism, and refused more often to provide treatment to the leprosy patients. Patients said they experienced social loathing from the nonprofessional workers more than from the professional workers. Nonprofessional or paraprofessional workers who worked in the general health service system had little experience with leprosy and lacked

formal training in leprology. These workers thus developed attitudes closer to those of the general public than to members of the health professions. At the health institution level, health personnel such as an assistant nurse at the district hospital studied still ostracized leprosy patients by refusing to treat those who had developed ulcers and deformities.

The Dynamics of the Stigma of Leprosy

Social structure of the community

The degree of discrimination directed toward patients with leprosy varied among individuals, depending on gender and social factors. First, men tended to display less discrimination than did women. This may be because men had greater social contact with patients than did women, owing to their physical mobility within and outside the community. Social contact and acquaintance with patients mitigated social loathing. Second, older people tended to discriminate against leprosy patients more often than did younger people. This may be because older people have had more negative experiences with severe cases of untreated leprosy than younger people have had. Third, close neighbours of leprosy patients tended to accept those with *khi thut* more than did neighbours who lived far away. Finally, the rich tended to discriminate against patients more than the poor did.

Although the general population in rural Thai society may fear these patients, and want to exclude them from the community, the reality is that they live in the cultural context of a small, homogeneous village setting where everyone knows everyone else. Villagers usually say they are all related to each other (*phi nawng* or "siblings"), by which they mean that they all live within the same community sharing the same values and destiny. The sense of relating to each other becomes very strong among a group of neighbours. Individual neighbourhoods generally exhibited a high tolerance in social contacts with patients with *khi thut,* and strong social or material support for poor patients who were their immediate neighbours. Patients were allowed to visit neighbours who lived in close proximity and engage in conversations within the group as long as they desired. The poor patients always received fish and food regularly from their neighbours. However, there were some exceptions when the relations were unequal in terms of economic status and power. A neighbour who was wealthy or held power due to prestige, such as a village headman, would express a more negative attitude toward patients and would avoid most social contact with patients even if they lived nearby.

Social class and power relationships

Stigmatization is a process involving two parties, consisting of at least one individual who does the stigmatizing and at least one who is the target. What must first be considered is the power relationship, that is, where each party stands in the social hierarchy, and who has more power in the relationship or situation. There is a difference in terms of the degree of stigmatization if a person is rich or poor, landlord or landless, employer or employee, adult or child, and so on. With respect to leprosy, people involved in such relationships will display different forms of behaviour, often dictated more by the power relationship, than by the disease. The economic class of people with leprosy is important to the extent that it plays a role in determining the degree of stigmatization they experience. For patients who are wealthy, leprosy and visible deformities do not completely limit their opportunities to achieve their goals. The poor, however, are already socially marginalized by their socioeconomic status. As a result, leprosy patients who are poor are twice shunned by society.

Although the community had a negative perception of rich patients with deformities, discriminating behaviour was rarely manifested, in contrast to the discriminating behaviour directed toward poor patients. Wealthy patients with deformities held higher social status than poor patients with deformities.

Historical factors affecting the dynamics of the stigma of leprosy

Before biomedical treatment for leprosy was introduced in the communities studied, the popular repulsion to leprosy arose more from the images of infected wounds, discharge of blood and pus, and disfigurement and unpleasant odour than from fear of contagion. Compared with an epidemic of smallpox, in which the incubation period is 1 to 2 weeks, leprosy is a slowly progressing communicable disease with an incubation period of from 3 to 15 years. Villagers viewed smallpox as a communicable disease but viewed leprosy as more hereditary than communicable. This is also due to the fact that people usually saw several leprosy cases within the same family or kindred groups. However, people had their own interpretation of germ theory and disease contagion for leprosy derived from stereotyped folk beliefs about the disease that involved living organisms that could jump from afflicted persons or their property to nonafflicted persons.

Modern health education, emphasizing leprosy as a disease communicable through skin-to-skin contact, blended well with folk beliefs concerning disease etiology, as well as with the Buddhist notion of leprosy as a communicable disease. As a result, in the period following the introduction by the state of Western explanations about how leprosy is spread, patients with open wounds, blood, and pus were reportedly more stigmatized than before because these bodily fluids were viewed as the route of transmission. The existing beliefs concerning leprosy combined modern and folk theories of contagion.

Following the success of the state's leprosy control programme, the disease was reclassified by the health profession as mildly communicable. In an attempt to destigmatize leprosy, health education messages emphasized that leprosy was not highly contagious, was curable, and that deformities could be prevented if patients took the appropriate drugs regularly and at an early stage. The concept of leprosy as a mildly communicable disease seemed to correspond with the villagers' preconception of leprosy as a hereditary disease.

However, health education had little impact on the destigmatization of leprosy. Leprosy stigma continued because of the cultural and societal meanings ascribed to the attributes of leprosy patients, namely, that they were unclean, immoral, sinful, incurable, and debilitated. In the communities studied these ideas were reinforced by the presence of poor patients and ex-patients with bodily disfigurement, everyday use of nonneutral discourse in talking about leprosy, and the use of leprosy terms as metaphors to convey the second layer of meaning of leprosy as an unclean and socially ostracizing disease.

Data from the present study show that concealing the diagnosis of leprosy by informing patients that they had only a simple skin disease had been practised by some leprosy health workers and some general health workers from the subdistrict health centre for four to five years. The idea of concealment was to prevent social ostracism of patients from the community and self-stigmatization by patients themselves. Leprosy health workers attempted to strip off the cultural meaning of leprosy as a severe, debilitating, highly communicable and socially ostracizing disease, and present it as a mildly communicable and not necessarily severe disease (if early treatment was sought). However, in so doing, leprosy health workers unintentionally constructed a new type of skin disease—*rok ruan* (leprosy), characterized as white patches that villagers viewed as a mild disease. While some believed that if *rok ruan* was not treated, it would progress into *khi thut*, many believed that *rok ruan* was a totally different disease from *khi thut* and that persons with *rok ruan* would never contract *khi thut*, as long as they did not have any relative with *khi thut*. On some occasions there were negative results, as seen in poor patient drug compliance as well as confusion and uncertainty in some patients as to whether their white patches truly represented leprosy. In order to resist metaphorical thinking and to reconstruct the popular image of leprosy, distorted information should not be presented to the community. Educational messages should stress the facts about the types and stages of leprosy.

CHAPTER 5

INDIVIDUAL AND FAMILY ADAPTATION TO LEPROSY

Leprosy is not a direct cause of death. Patients may live many years following diagnosis and be capable of leading productive lives (Gussow, 1964:180). However, because of the stigma attached to the disease and the progressive symptoms and debilitation, patients and their families need to adjust and adapt on a number of social, interpersonal, economic, and psychological levels of functioning. This chapter explores (1) patients' and families' coping in terms of strategies for stigma management, (2) the effects of leprosy on patients and their families and their adaptation, and (3) group formation among patients and communities.

Coping with Stigma: Strategies for Stigma Management

Regardless of the form adapting to stigma takes, coping strategies enable individuals to interact with their communities more comfortably, as well as to be more acceptable during social intercourse.

Information management and concealment

Goffman suggests that people who are discreditable often confront their problem in terms of "information management," that is, they consider whether "to display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where" (Goffman, 1963:42). Leprosy patients with no visible deformities develop a strategy that Goffman (1963) calls "passing." This involves disguising those aspects of leprosy that will elicit stigma by controlling and concealing information, and denying their disease, which would discredit them in the eyes of others. All patients want to conceal their disease from the public. Although patients who developed the early stage of leprosy with skin patches only were not condemned by the community, they usually concealed the fact that they had leprosy from family members, other relatives, and neighbours. Patients usually chose not to tell their spouses, family members, and neighbours about their leprosy as long as they could maintain secrecy.

Covering

Leprosy patients with visible deformities are fully discredited, and their appearance makes information management impossible. These patients still want to avoid "publicizing" their tainted attributes, so they develop strategies to minimize social ostracism. Goffman's term for such stigma management is "covering."

Covering visible bodily deformities with clothes, handkerchiefs, hats, sunglasses, powders, socks and shoes, and so on was commonly practised by leprosy patients. Various covering techniques enabled patients to feel more comfortable, although they might not have changed the prevailing stigmatized images. Another covering technique involved avoiding referring to the disease in local terms (*khi thut*).

Destigmatization

Destigmatization is the process by which the deviant identity of a person is replaced with one that is essentially nondeviant or normal (Pfuhl, 1986). Leprosy patients with severe deformities develop similar patterns of destigmatization. All of them enjoyed telling others that their neighbours, relatives, and families did not shun them and, in fact, gave them material and social support.

Confronting stigma

Some visibly stigmatized leprosy patients coped with stigmatization by confronting the condemnation. Some confronted the stigmatizer with threats or violence, others with a fatalistic attitude. For example, Jam, the severely deformed patient, would get angry and yell at neighbours or children who stared at or mocked her leonine facies. These people later did not dare to mock her face again.

"Patient's Career": The Effect of the Stigma of Leprosy, Psychological Transformation, and Adaptation

As soon as a person is diagnosed as having leprosy, he or she becomes shocked and frightened. All patients developed a high level of anxiety and fear of being ostracized from the community, of the progressive deterioration of the disease (which would lead to deformities), of the loss of ability to earn a living, and of spreading the disease to family members. Patients who were parents worried that their children would be affected by the stigma, that this might lead to their being shunned, and that loss of opportunity for marriage and family would result.

If the symptoms improved with the passing of time, patients felt less anxious and depressed. They also felt more comfortable in social relations with family and community. Anxiety, and fear of ostracism, of progression of the disease, and of disease contagion decreased when patients were taking medicine and saw improvement in symptoms. Anxiety and fear fuelled the desire of many patients desire to regularly maintain their drug intake in order to be cured. Most patients tended to trust the Western drug regimen. The health workers from the leprosy centre always confirmed the efficacy of treatment, which decreased patients' anxiety and increased drug compliance.

In contrast, when symptoms did not improve or worsened after taking the drugs for a period of time (which occurred often with patients on monodrug therapy), patients often became more depressed. Several informants drank alcohol as a way of coping with their depression.

Rejection by the community was the most commonly expressed fear for patients under treatment. This was especially true for those who developed visible deformities. Those still taking medication who were unmarried did not want to court anyone or have any romantic relationships. They thought of themselves as being diseased.

Another emotional effect of the stigma of leprosy involved shame and self-pity, because persons with leprosy believed they had a disease that would lead to social ostracism. Many persons afflicted with leprosy considered leaving their families and communities or committing suicide. The feeling of shame increased when they developed drug reactions (such as body swelling, redness, nodules), ulcers, or visible deformities.

Fatalism

Over time, many with visible deformities developed a fatalistic view toward their physical and psychosocial problems. Influenced by the Buddhist notion of karma, fatalism is an adaptive psychological strategy for coping with affliction.

Fear of being diseased

After being discharged from the drug regimen, most patients still feared a "relapse" of leprosy. Although these patients were now completely "cured," as there were no bacilli in their bodies, a number of them (15 of 35 ex-patients) suffer from an abnormality due to nerve damage caused by bacilli during the

earlier treatment period (e.g. leg pains, anaesthesia, cracks in the skin, ulcerations). These patients lived with the worry and fear that they were not completely "cured" and that their disease might worsen.

Medical and physical logistics

One of the more serious health problems that people with leprosy who have already developed deformed hands and feet may suffer involves chronic, deteriorating bodily conditions. This includes ocular damage and inflammation causing redness and some tearing, blindness, chronic ulcers (especially foot ulcers), perspiration, and chronic and deep skin cracking of the feet. Of 57 informants, 17 developed paralyzed, anaesthetized, and disfigured hands and feet, as well as chronic ulcers, and 4 other informants had eye problems (severe corneal ulcers, inflammation of the eye, eye infection, and blindness). These patients faced difficulties working in the rice fields and performing such routine daily physical activities as cooking, eating, walking, and foraging. In addition, health problems were exacerbated due to conditions associated with working in the rice field, including handling rough tools, walking in the muddy field, and exposing their eyes to the sun.

Social and economic aspects

Social and economic aspects of the lives of patients with white patches only did not change with the onset of the disease. None of the patients with a visible deformity left the community. Rarely did patients migrate because of family and community ostracism. Of 57 informants, only one (not visibly deformed) left the community to stay in the leprosy village due to family ostracism.

Some patients stopped working in the rice fields because of hand and foot deformities, since deformities are an obstacle to engaging in rice cultivation. When a male patient who is a breadwinner has deformed hands and feet and cannot work, it affects the family's financial status significantly since the family loses its main workforce for rice cultivation. Those with *khi thut* restricted their physical mobility within the village, no longer working outside the village or in their rice fields. It is also difficult for family members whose spouses or parents have bodily deformities to leave these patients and work as wage labourers outside the village. The disabled patients needed family members to assist them in such activities as cooking, obtaining water from the pond, and so on. As a result, families lose needed extra income and face increased poverty.

Effects on Patterns of Familial Relations: Psychological and Behavioural Transformation and Adaptation

The predominant family response after learning that a member had leprosy was fear: fear of contracting leprosy from the patient and fear of being ostracized by neighbours. With time, the fear of contagion decreased, especially when there was improvement in symptoms. Feelings of grief, shame, and worry over the patient's health were also common. Children of patients tended to have a more negative emotional response to the situation than did spouses. Some children responded with anger toward the health workers who had diagnosed the patients. They denied their parents' disease. Some cried on learning of their parents' affliction.

However, most relations between patients (with and without deformities) and family members remained normal. Most of the family members of *khi thut* patients who were already stigmatized chose to embrace the patient regardless of the potential courtesy stigma[6] that would be attached to them. Only one out of 49 married patients and ex-patients that I interviewed chose to permanently leave her husband out of fear of catching the disease. The rest remained married. They continued to sleep with their spouses

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[6]Courtesy stigma means stigma attached to a relative or close friend (Goffman, 1963).

and engage in sexual intercourse. Of 49 married couples, only one patient (female) began sleeping separately from her spouse and has continued to do so for approximately five years. She had developed nodules and ulcers and was afraid that her husband would be disgusted by her. However, her husband still came to her bed and engaged in sex with her quite often. She became pregnant every two years after she had leprosy. Another woman who was Jai's wife told me, "I have never slept separately from my husband since he has been sick with leprosy. It is useless to do that because we are husband and wife. If I sleep separately from him, he will come to sleep with me anyway. When he has a sexual desire, if I am not ready for him, he will get mad."

It is interesting that patients' bodies are apparently not viewed as unclean from the perspective of most spouses. Patients were accepted by their spouses because of the strong marital bond. Wives of patients still allowed their husbands sexual contact even though they had some fear of contracting the disease. This phenomenon reflects the relative subordination of women to men in Thai society, where husbands usually control the initiation and frequency of sexual contact. Still, all spouses of patients expressed fear of contagion, worrying constantly that they might contact leprosy from their spouses, and continually visiting the leprosy mobile team health workers to ask for medical check-ups. Some of my female informants married to patients had thought about divorce or running away from their husbands, but they ended up staying with their spouses. The reasons that stricken families rarely divorced or separated were (1) the strong marital bond and the deep love that the wife felt toward her afflicted husband, which helped her to overcome the revulsion; (2) the wife was unable to support herself and her children independently (most of these women were poor and had no land); and (3) most women were concerned for their children's future.

In peasant Thai society parent–child relations are based on respect, loyalty, and obedience. These social relations are taught within the family from an early age and traditionally form the basis of the social organization of Thai society. Children of patients still respected, nurtured, and provided care for parents who were unable to help themselves. In the villages studied, every patient with bodily deformities who had no spouse had either children, a niece/nephew, or a brother/sister staying with them, preparing meals for them, or supporting them financially.

Eating and sleeping together in the same house are codes of behaviour for familial relations. Refusing to eat or sleep with family members would be considered immoral. Although family members were afraid of contracting leprosy by eating or sleeping with patients, they usually did not ask for separation unless initiated by the patients. In-depth interviews revealed that 6 out of 57 informants separated family eating utensils. These were patients with visible disfigurement who were afraid that their relatives would be disgusted by them. For example, Pun stated: "I told my family to find me a separate bowl, plate, spoon, and food. I was afraid that my family would be repulsed by me when we ate together."

Family members of leprosy patients also feared being ostracized by neighbours. Because of the folk belief that leprosy is inherited through blood, fear of stigma was more intense among children of patients than among spouses. The children suffered because of fear of being shunned by friends, loved ones, and neighbours, as well as because of the potential loss of marital opportunity. Faced with the potential effects of courtesy stigma, patients' family members often developed the same pattern of stigma management as the patient. They concealed, and denied to others, the fact that they had a family member who had leprosy.

Group Formation

Understanding the development and maintenance of group formation among leprosy patients, and between patients and nonpatients in the community, is important in understanding any collective action such as community participation in the leprosy control programme.

The process whereby leprosy was stigmatized did not promote group solidarity among leprosy patients. Tuberculoid-type patients, with white-skin-patch symptoms, always differentiated themselves from patients with disfigurement and ulcers by denying that they had leprosy. Patients with disfigurement and ulcers, in turn, attempted to avoid any public association with other *khi thut* patients because it would call attention to their own stigmatized condition. Because of differences in patient socioeconomic class, gender, and age (see Table 3), there were no ongoing or daily social relations among patients in Noan Pa village. During this study, no leprosy patient was overheard mentioning a shared "we-feeling," or the sense that patients belonged together.

It was very difficult to initiate any group action among the leprosy patients in Noan Pa village. For example, I asked patients if they had been trained by health workers in preventive self-care (e.g. dressing open wounds, massaging and stretching their fingers and toes) and, if so, whether they could teach other patients. Most refused this request because of the repulsion of touching other patients' ulcers or deformed hands and feet. Some ex-patients felt they were suffering from a state of "bad" blood that increased their susceptibility to a "relapse."

In Noan Pa village, seven village health volunteers (VHVs) were selected by the subdistrict health worker to perform primary health care activities. These were young and middle-aged females who had never engaged in any community health work except for collecting health statistics for the midwife. When asked whether they could teach *khi thut* patients to practise self-care for disability prevention, they refused to teach or touch the patients' bodies. All of the VHVs held negative attitudes toward *khi thut* patients. They were afraid of contracting the disease and felt repulsed. They had poor knowledge of the etiology of leprosy, and maintained misconceptions about the disease (e.g. leprosy is highly transmittable and can be transmitted through touch, especially ulcerations).

There were only two traditional healers in Noan Pa village, both elderly male. They emphasized the use of herbal medicine in their practices. Both reported that they would not have an aversion to *khi thut* patients if they had to provide treatment or teach them self-care for disability prevention. They viewed it as a part of their work as traditional doctors to prevent patients from developing physical deformities.

Information on group formation has implications for planning an effective community-based self-care programme in Thailand, which will be discussed further in the final chapter.

CHAPTER 6

RECOMMENDATIONS

Suggestions and recommendations derived from the knowledge gained in this anthropological study of the stigma of leprosy in rural North-East Thailand follow. The discussion focuses on strategies for developing relevant educational materials to facilitate destigmatization, as well as to develop a self-help rehabilitation programme.

Health Education: Destigmatization

Educational messages in Thailand (and possibly in other parts of the world as well) concerning leprosy should be designed to eliminate the fear of disease contagion and repulsion. In addition, these messages ought to promote modification of culturally stereotyped beliefs that still exist. Certain aspects of existing popular beliefs concerning disease etiology might be utilized to design health education messages. Leprosy health workers, and those involved with health education programmes for combatting the stigma of leprosy, need to be aware of the significant impact that social and cultural constructions have on producing the stigma surrounding leprosy. Health professionals should be made aware of how stigma is produced, and how it is directly related to their activities. Health education messages should be reviewed with the purpose of eliminating messages that create or reinforce the community's fear of the disease. I suggest that the words "leprosy as the disease of social loathing," which are literally translated from "*rok ruan—rok sungkhom rungkhiat*" (in Thai) be eliminated and not be used anymore by health educators or in health education materials. Pictures of severe and open ulcers in health education messages arouse aversion to leprosy patients in the community and should be discarded. Health practitioners at every level should be well educated about leprology, especially the transmission of the disease. As I discovered in this research, knowledge of leprosy and fear of leprosy are inversely correlated.

Educational materials for lessening the stigma of leprosy need to be designed to fit the unique cultural context of each particular region. In the educational material for the North-East Thai population, for example, the folk concept of *mae* (small animal-like organisms) can be used as a substitute word for the bacterium *M. leprae* that causes leprosy according to the biomedical model. It can be emphasized that the *mae* of *khi thut* are not highly contagious, and are transmitted only via nasal droplets. It can be stressed that *mae* are not transferable through physical contact, sharing food, and so on. Villagers already understand the concept of "immunity." In order to destigmatize the fear of disease contagion, the concept of the existing immunity of the adult population should be emphasized. Villagers should be informed that only leprosy patients who never take medication and are at one particular stage of the illness can spread the disease. Because the community has strong faith in Western leprosy drugs, it should be emphasized that the chances *mae* will be transmitted from one person to another is reduced if the patient has taken the drug regularly for a prescribed period of time.

The cultural stereotype of leprosy as an incurable and debilitating disease can be modified more rapidly if the leprosy control programme succeeds in preventing deformities in the patient and ex-patient population. Even now, there is evidence of a trend in the reduction of stigma associated with leprosy. This study reveals that young people had less negative attitudes, and shunned people with leprosy less than older people. This appears to be because they had personally seen fewer cases of patients with deformities. The fear and the stigma associated with leprosy persist because the community still sees patients with deformities.

Because communities continue to view leprosy predominantly as a disease characterized by body disfigurement and ulceration, communities should be informed about the stages and types of leprosy.

Data from the field also show that persons with symptoms such as white patches, joint pain, and loss of sensation did not seek care because they did not consider themselves to have leprosy. The community should be educated about these early signs of leprosy.

Laws and norms in formal and nonformal codes need to be changed. For example, marriage laws presently allow a person to obtain a divorce if the spouse has leprosy, and government hiring applications continue to reinforce the marginalization and ostracism of leprosy patients and ex-patients as well as regard leprosy as a "severely communicable disease" (e.g. one sentence in the government job application form asks: "Do you have a severely communicable disease such as leprosy?").

An initial diagnosis of leprosy is extremely traumatizing. Educational materials should be designed to display messages that help patients to cope with the psychological and social effects of the disease at the time of diagnosis. There is also a need for health workers who diagnose and give treatment to encourage patients to overcome their feelings of shame and fear, for example, similar to post-test counselling provided to people tested for human immunodeficiency virus (HIV).

Secrecy and denial as coping mechanisms of patients should be considered. When providing services in the community, leprosy workers need to be sensitive to the stigmatizing process that may affect patients. For example, it may be preferable not to visit household contact cases at schools, or to announce the names of leprosy patients for case holding in the village. The right to privacy, as well as and the right of patients to withhold their names from public, should be considered. This is a basic right to which a patient with any stigmatizing disease (such as AIDS) is entitled. As Pearson (1988) notes, the meaning attributed to leprosy as an illness that leads to social ostracism must be considered in approaches to health care planning.

Educational materials for destigmatization should build on Buddhist notions of compassion and merciful acts. It should be emphasized that a good Buddhist must not ostracize persons with a disease like leprosy (or AIDS), since they have suffered enough without the added strain of ostracism.

Self-Help Therapeutic and Rehabilitation Programmes

Owing to advances in medical technology, particularly the development of an effective chemotherapeutic programme, MDT has currently become the most effective means for controlling leprosy in developing countries such as Thailand. The rapid decrease in the prevalence rate of leprosy in Thailand raises the real possibility that leprosy-free zones can be established in many areas of the country. However, there is still a need to help ex-patients successfully reintegrate into their communities.

The Thai government's leprosy control programme has not been fully successful in preventing disabilities or in rehabilitating disabled persons who have otherwise been successfully treated. Such an accomplishment would surely improve the quality of their lives. In this study, the incidence of those who developed disabilities was high (17 of 57 informants, or 29.8 percent). Although leprosy workers currently offer health education about self-care practices for prevention of deformities, in reality these efforts seldom affect patient practices. In-depth interviews revealed that none of the patients who were taught self-care complied with suggestions, except for a few patients who would occasionally apply olive oil that they bought with their own money to their bodies. All patients had only vague ideas about the advantages of self-care practices. They did not realize that deformity could be prevented. On the contrary, they believed that deformity is a stage of leprosy that could not be avoided if a person did not take any drugs.

Disability prevention and rehabilitation need to be given a high priority in Thai leprosy control policy. Community-based self-care programmes and procedures should be sufficiently flexible to be incorporated

into the existing social structure and everyday life of patients. The ethnographic data mentioned earlier showed that family alliances still remain strong among patients, their children, and their spouses. Thus, community-based rehabilitation programmes could be focused at the individual and family level rather than at the community level. The programmes could focus on educating patients and their family members to be relatively independent in caring for leprosy-related problems.

Existing community social structures must be identified to alleviate the burden on thè family or to substitute for family support where it is missing. Mobilizing community participation through volunteers, village leaders, or other community members is often not helpful since most (except for some local healers) still view leprosy as a loathsome disease. A better solution, given the tradition of strong neighbourhood ties, would be to train patients' neighbours (together with patients' families as a self-help group) to help patients care for their health problems. The present study also revealed that many local healers were not repulsed by patients' ulcers and body deformities. One local healer had treated a *khi thut* patient for her ENL (*erythema nodosum leprosum*) reaction by using herbs. Local healers who do not shun the leprosy patient should be mobilized to advise patients and families on strategies for preventing deformities.

Educational messages given by leprosy staff to patients and their support groups should emphasize measures to prevent bodily injuries. Patients who experience sensory loss in hands and feet must learn to adapt their everyday routines in order to prevent further disability. For example, they must realize that even the smallest ulceration can be potentially serious. The patient, with the assistance of his or her support group and health worker, must identify routine daily tasks that may cause injury, and take preventive measures. The prevention of ulcers and disabilities requires a high level of motivation. Patients must continuously maintain such preventive behaviours as hand exercises to prevent contracture in paralyzed fingers, soaking the feet in warm water, and massaging the hands and feet with skin lotion or oil. The process requires close and regular supervision, and follow-up from the health worker. Health workers should make regular home visits to the patients' family (at least two times a month). This can be arranged in conjunction with the community work of the health worker from the health centre.

At the present time, an adequate referral system is not available for patients who require more extensive treatment, such as eye or hand surgery. An efficient referral system for these patients must be developed in order to prevent potentially more serious deformities. The availability of medical supplies should be improved to facilitate the prevention or rehabilitation of disabilities: shoes for the patient who has footdrop, sunglasses and ocular antibiotic medicine for eye infections, topical antibiotic medicine for ulcers, olive oil for skin cracks, and so on. The health station should be equipped with these supplies. These services can deal directly with patients, or through the village committees together with effective technical support from the Leprosy Zonal Centre, leprosy colony, and district hospital.

This research has also focused on the social structure conditions associated with those who have leprosy. North-East Thailand, which is considered to be the poorest part of the country and the area to which the government has allocated the fewest resources for development, has the highest prevalence rate of leprosy in the nation (3.31 per 10 000 in 1990). Like other infectious diseases, leprosy primarily affects the poor, and its widespread occurrence in this region reflects the collective problems of Thai society, namely, low income, malnutrition, and poor living conditions. Uneven resource allocation exacerbates the occurrence of many infectious diseases, including leprosy.

The successful prevention of leprosy and rehabilitation of ex-patients require confronting the societal and political problems of the country. This involves addressing poor people's lack of mainstream participation in the country's development, their economic deprivation, exclusion from the political and educational processes, lack of land, and poor opportunities for employment. Preventive and

rehabilitation programmes will not prove successful unless the government and health planners realize that unfavourable sociopolitical factors undermine programme efforts.

It is clear that poverty and economic deprivation are important obstacles for those who have leprosy and who have developed deformities. Efforts to teach preventive behaviours in order to curb the development of deformities will not be successful if patients must struggle for daily survival in conditions of economic deprivation and hunger. Poverty also exacerbates the problem of stigmatization for those afflicted with leprosy, and prevents them from fully reintegrating into the community. They are twice marginalized and excluded from society—by their socioeconomic status and by their disease. The folk concept of leprosy as the "unclean" disease, which partly creates repulsion and leads to stigma, is based on the social features of patients who are very poor. Government policy for any leprosy control programme must acknowledge that leprosy is foremost a social, economic, and psychological problem, rather than merely a medical problem.

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